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British Columbia Persons With AIDS Society

The British Columbia Persons With AIDS Society seeks to empower persons living with HIV disease and AIDS through mutual support and collective action. The Society has almost 4000 HIV+ members.

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think+

opinion and editorial

Speaking out about depression

by Glen Bradford

The stigma of depression leaves many of us feeling isolated and seeking answers. Psychosocial factors such as limited social support, restricted financial resources, and poor access to health care contribute to this debilitating condition. It crosses all HIV-positive populations.

"Retirement" at an early stage in our careers can leave young adults depressed and wondering if they will ever have a future that includes education or returning to work. The lack of opportunities to socialize with fellow PWAs erodes our ability to stay emotionally healthy. This is especially challenging for those confronted with AIDS stigma and isolation in their communities.

Multiple mental health issues are associated with the combination of intravenous drug use and poor adherence to HIV treatment regimes, which can accelerate the likelihood of an early death.

We know that HIV attacks the brain, causing inflammation and tissue deterioration. HIV also causes several neurocognitive disorders that can lead to clinical depression. Many people with HIV also have mild or moderate problems associated with the brain, causing slower thought processing and difficulty with memory and focus. Certain antiretroviral drugs are also responsible for psychological symptoms.

Greater severity in HIV disease—such as high viral load, decreased CD4 count, physical disability and fatigue and an increased sense of hopelessness regarding physical health—compounds the possibility of depression. Depression, in turn, compromises the immune system, creating a downward spiral of disease progression.

The percentage of men with psychosocial problems who report high-risk sex activities is five times greater than among men with no mental health problems. This leads to an increase in new HIV infections. The most common psychosocial problems are multiple drug use, partner violence, a history of childhood sexual abuse, and social anxiety disorders. These findings direct us toward critically needed, sophisticated prevention programs that address the psychological and social issues that influence HIV risk.

Antidepressants may improve our moods but they have side effects that leave us with physiological problems such as the lack of a healthy sex drive. HIV-positive people have a right to a healthy sex life. Stunting our sex drive is not effective transmission prevention.

We need access to mental health professionals who offer specialized knowledge of the interaction between psychiatric and HIV drugs. In order to live healthier lives and eliminate HIV transmission, we need to move past the shame and admit that depression is a major issue for many of us.

If you're HIV-positive and suffer from depression, you are not alone. It's time to share our collective stories. By doing so, we can demand that PWAs have improved access to appropriate mental health care. This is critical if we intend to stay physically and mentally healthy; it's also critical to prevent the spread of HIV. Our lives and the lives of others depend on it. ⊕

Glen Bradford is the chair of the BCPWA Society.

Living+ is published by the British Columbia Persons With AIDS Society. This publication may report on experimental and alternative therapies, but the Society does not recommend any particular therapy. Opinions expressed are those of the individual authors and not necessarily those of the Society.

REALITY BITES

Government approves rent increases

Your landlord could be coming after you for a big rent increase because of recent changes to provincial law that took effect January 1.

Any landlord can legally increase any of their tenants' rents by up to 4.6 percent this year, and there's nothing you can do about it. If you have a pet, you can be charged an extra half month's rent for a "pet damage deposit."

There's more. *If you agree in writing*, your landlord can raise your rent by any amount. And if your rent is "substantially lower" than average rents for places like yours in your building or neighbourhood, your landlord can raise your rent to that average. However, you can appeal this kind of rent increase.

If your landlord asks you to pay more than a 4.6 percent rent increase, *do not agree, and do not sign anything*. Call a BCPWA Society advocate at 604.893.2223 (toll free at 1.800.994.2437 extension 223).

Compassionate access to tipranavir

German pharmaceutical company Boehringer-Ingelheim has introduced a small compassionate access program for tipranavir, a protease inhibitor in phase II/III trials. The program permits access to the drug for people who cannot create a viable drug regimen without tipranavir.

In Canada, doctors must submit an application on behalf of their patients to the Health Canada Special Access Program. The Canadian Treatment Action Council is interested in hearing about any cases where applications are turned down. They can be reached via telephone at 416.410.6538 or by email at <ctac@ctac.ca>.

BCPWA secures welfare changes

The BCPWA Society has secured legislative changes to welfare regulations.

In April 2003, the Ministry of Human Resources discontinued the monthly dietary allowance to persons receiving "grandparented" Schedule C benefits.

The BCPWA Society was able to lobby the government to overturn the decision. As of June 2003, all PWAs in the province receiving Schedule C once again receive the dietary allowance. This benefit totals over $250,0000 annually for BCPWA members.

In August 2003, the government amended the Persons with Disabilities Regulation to authorize payment of a diet supplement to persons who have grandparented tribunal appeal awards under Schedule C.

Abbott hikes price of ritonavir

Abbott, the manufacturer of the protease inhibitor ritonavir, made an unexpected and unilateral decision to increase the price of ritonavir (Norvir) by 400 percent in the United States.

The pharmaceutical company justified the decision by saying that other companies are using ritonavir as a booster for their drugs, thereby giving those drugs more and longer market share. The company feels it should therefore receive a "royalty"; since it cannot collect a royalty, it is raising the price.

The Patented Medicines Pricing Review Board, the Canadian body that governs pharmaceutical prices in Canada, allows annual cost increases of up to 5 percent to adjust for cost of living. Abbott is therefore increasing the price of ritonavir in Canada by 5 percent.

Professorship in memory of Glen Hillson

GlaxoSmithKline has donated $1.8 million to the BC Centre for Excellence in HIV/AIDS (BCCfE). The BCCfE has decided to use this money to establish a professorship in clinical virology in the Faculty of Medicine at the University of British Columbia, in memory of Glen Hillson. Hillson was the BCPWA Society's chair from 1998 until his passing on June 12, 2003.

"We are very pleased to name this position to honour Glen's remarkable contribution to the field of HIV/AIDS in British Columbia and in memory of his contribution and support to our organization," says Brian Harrigan of the BCCfE.

Hillson, who had virtually no post-secondary education, would be thrilled and gratified by this decision.

Crystal meth a barrier to adherence

A recent study found that methamphetamine abuse was a barrier to HIV medication adherence among gay and bisexual men. The research explored medication adherence among 23 HIV-positive gay and bisexual methamphetamine-abusing men enrolled in an outpatient drug treatment research project.

Substance-use barriers to adherence were coded into two main themes: planned non-adherence, and unplanned non-adherence. Planned non-adherence was a strategy for coping with demanding HIV medication schedules, or was linked to sexual behaviours while using methamphetamine or to fears of interaction effects from mixing methamphetamine with HIV medications. Unplanned non-adherence to HIV medications was linked to methamphetamine-related disruptions in food and sleep schedules

REALITY BITES

The findings are helpful in designing culturally specific HIV medication adherence interventions for this population. Medication adherence among persons with HIV infection is important not only because of the effect of non-adherence on an individual's health but also because non-adherence can lead to medication-resistant viral strains.

HIV liver transplant survival is comparable

The findings of a study reported in *The Journal of Infectious Diseases* suggest that survival of HIV-positive liver transplant recipients does not differ from that of HIV-negative liver transplant recipients, thus suggesting that HIV infection should no longer be a contraindication to orthotopic liver transplantation (OLTX).

With immune function restoration possible with highly active antiretroviral therapy (HAART), researchers evaluated 24 HIV-positive subjects with end-stage liver disease who were undergoing OLTX after the availability of HAART. The cumulative survival among HIV-positive recipients was similar to age- and race-comparable HIV-negative recipients. Survival was poorer among subjects with post-OLTX antiretroviral intolerance.

The researchers acknowledge that the small sample size, short follow-up, and subsequent small number of deaths limit both the long-term projection of survival after liver transplantation and the elimination of confounders that might explain survival differences among recipient subgroups. However, they note the findings warrant further large prospective studies.

Source: NATAP <www.natap.org>

US Congress harasses researchers

An editorial in *Nature* magazine reported that last October, 180 researchers funded by the US National Institutes of Health (NIH) started getting phone calls from the agency's headquarters. The researchers are conducting studies into such subjects as homosexuality, sexually transmitted diseases, and the use of illegal drugs. They were told that their names were on a list held by a Congressional committee that oversees the NIH, and that they might expect inquiries from its investigators.

The list, compiled by a religious lobbying group, has already drawn the attention of prominent Republican members of Congress, which asked the NIH to explain the medical and public-health relevance of the highlighted projects.

This was the second time in 2003 that Congress has turned a spotlight onto projects that have already been vetted by the peer-review process.

We want your input

Are you currently taking synthetic human growth hormone to combat HIV-related side effects, or have you taken it in the past? The BCPWA Society is trying to gather anecdotal information on people's experiences with this drug. Was it effective? What did you do to increase its effectiveness? How long were you on it? What happened after you stopped taking the drug? How are you paying for this drug?

For a one-on-one, confidential conversation, please call Glen Bradford at 604.893.2316 or email him at glenb@bcpwa.org. ⊕

BCPWA Society volunteer Wayne Moore introduced Lloyd Axworthy at the World AIDS Day event at the Carnegie Centre in Vancouver.

Where there's a will there's a way

Everyone should prepare a will

by Raymond Campeau

An important document that you should have in your legal affairs tool kit is a will. It comes into effect only upon your death and speaks on your behalf once you have died.

Remarkably, most people postpone writing a will.

The following information applies only to British Columbia. Every province has different legislation that regulates estates and wills. Once you have written a will, you are absolutely free at any time to cancel it, change it, or dispose of anything you mention in the will.

A will should do three basic things:

- Appoint an executor to take charge of your affairs,
- Provide for payment of your debts, and
- Provide for all of your property to be divided as you wish.

A properly drafted will must reflect your intentions as accurately and clearly as possible. If it is vague or unclear, the result will be, at best, delays, and, at worst, litigation. If you have property and a substantial estate, you may wish to consult a lawyer to assist in the drafting of your will. However, in British Columbia, a legally binding will does not require anything special from a lawyer. No standard words or phrases are necessary in a will. But you must follow several steps, and you must meet certain requirements for your will to be a valid document:

- At the time you write the will, you must have "testamentary capacity." In other words, you must be of sound mind and understand what you are doing.

You must meet certain requirements for your will to be a valid document.

- In British Columbia, you must be 19 years or older. (Exceptions do occur.)
- A will must be in writing, either typed or handwritten. It cannot be video- or audio-taped.
- You must sign the will in the presence of two witnesses. They, in turn, must witness your signature at the same time in your presence.
- IMPORTANT: Witnesses cannot be beneficiaries of your will, nor can witnesses' spouses be beneficiaries of the will. Witnesses must be 19 years or older.
- If you are unable to read or sign the will, provisions are available for you to acknowledge your will and keep it valid.

All of the above steps are crucial, otherwise your will can be considered invalid, in which case the government, by way of legislation, will dispose of your estate.

Many people believe that a holographic will is valid. This type of document is not witnessed and is written entirely by hand. In British Columbia, a holographic will is not valid, with two exceptions:

- A mariner or seaman at sea or in the course of a voyage, or
- A member of the Canadian Forces on active service under the National Defence Act, or a member of the naval, land, or air force, or any member of the British Commonwealth of Nations or any ally of Canada while on active service.

If you want to make changes to your will, you may execute a codicil. This addendum to, or amendment of, the original will can add to, subtract from, or change the original will in any way you wish. It is important that it be prepared in the same way you prepared your will, using the same witnessing procedures.

The reason so many of us hesitate to write our wills is perhaps that it lays bare the heart. Nonetheless, a will lives on after one's death, and it can prevent a lot of heartache and headache for those you leave behind. ⊕

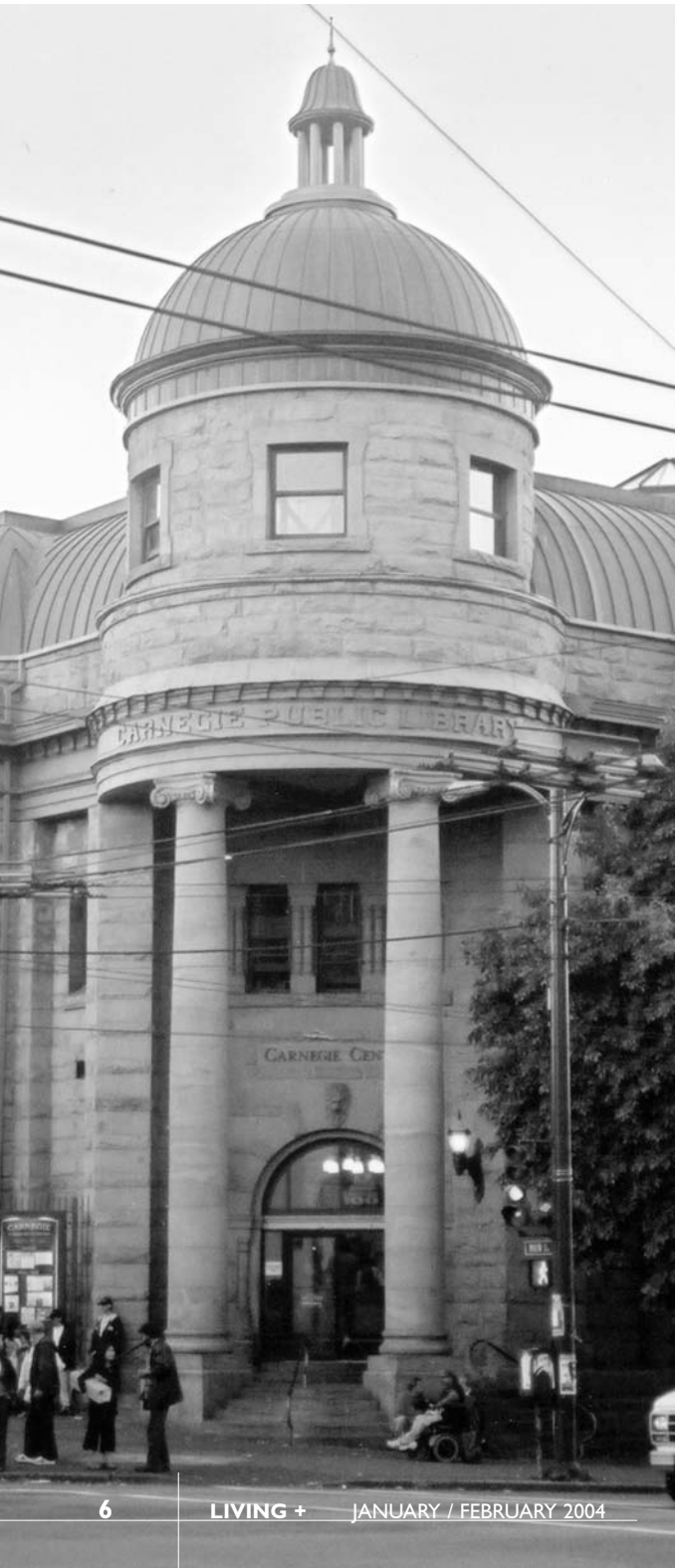
Note: This article is for information purposes only and should not be considered as legal advice.

Raymond Campeau is an assistant to the Treatment Information Program and Advocacy Department at the BCPWA Society.

A day in the life

A PWA in the Downtown Eastside tells his story

by Arthur Weiss



Dawn has not come. It is still chilly outside. Bodies wrapped in blankets to keep warm. Talk of the safe injection site goes on with three local users. Someone seeking "shake." Crack addicts looking for rock. Maybe some in the sidewalk cracks. Bending over, they search, eyes kind of glazed. People go up and down Hastings. Some sleep on the steps of First United. Wrapped up in anything they can find.

Seven a.m. People eating soup they got from one of the many outlets on Cordova. Needles are wherever you look. So are people's possessions—and they don't care.

Seven-thirty. Many of the regulars line up on the steps of the First United to get in. "Got shake?" "What you got to trade?" Usual talk; everyday. Joints are rolled and smoked while waiting.

Eight-fifteen. The throng of people multiplies. "Don't crowd me, man!" "Stop pushin'. It ain't open yet. Fifteen minutes." Everyone wants to get in first. There are clothing tickets being given out (Monday, Wednesday, and Friday). Soup and bread. People throng into the kitchen to get two or three cups of soup. Hungry, hungry. Someone brings out donated books and magazines. Crowding in, they grab and grab. How many of those books get sold to provide the next fix?

Nine a.m. The volunteers for the clothing room come down the steps. "Five ladies, five men." They go by the numbers given out. "Ten minutes." That's all you get to look around. One item from each area. "Only one shirt. You got two. Put one back. Only one coat!"

Someone asks, "Got any socks or underwear?"

"Time's up! Time's up! Gotta go!"

You go downstairs, hauling whatever you got from upstairs. "Coffee, need coffee…." Coffee and sandwiches at nine thirty. Everyone lines up to go in for coffee. The disabled use the first door. They get in first.

"What kinda sandwiches ya got? Tuna, I'll have tuna."

You sit down and have your coffee and sandwich. Sometimes they give you pastries. That's a treat! People wander

around inside and outside. Waiting, waiting. Time just melts into itself.

Eleven a.m. People line up for lunch tickets. Actually, they're not tickets. You sign up on a sheet and get a stamp on your hand. It's part of the "Program." Lunch is over at two p.m. People leave and go to other places like the United Gospel Mission, the "44".

Monday through Thursday, the Franciscan Sisters give out clothes between nine and eleven a.m. Men's clothing only. "Five at a time." Once you enter, you have to check any bags you have before getting any clothes. Once a month is what the sign says. Some come back more than that. It's the system. They know how to work it.

People throng into the kitchen to get two or three cups of soup. Hungry, hungry.

Back to Hastings Street. Hang out at the Carnegie Centre. Lunch is cheap there, but it's free at First United. After the first sixty people, they close the lunchroom door and a sign is placed outside it: "Full House." In come a few late stragglers. "Any more lunch? All full? Man, I'm hungry! Didn't eat anything today!"

"Sorry, full house," replies one of the kitchen volunteers. They haggle and try to get in, but they are told to go out into the waiting area until twelve-thirty. Then they can get coffee. Sometimes if there are extra plates, they bring them out into the waiting area and give them to the few stragglers there.

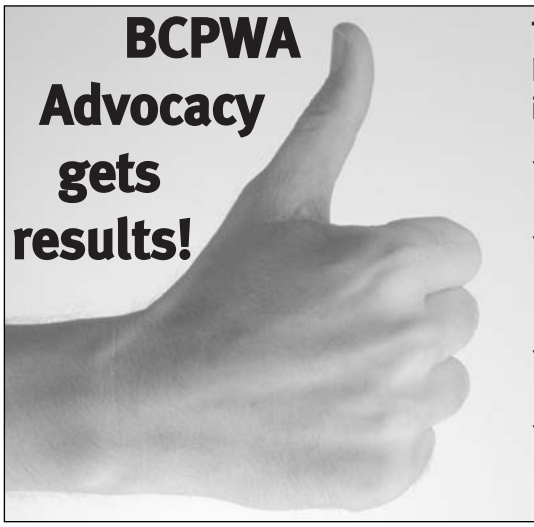
On some days, they have dinner. Tickets are given out at nine a.m. for five-fifteen dinner. Every morning when the place opens up and people get their clothing tickets, they make a beeline to the office window to get personal care items. Razor, soap, shampoo, toothpaste, toothbrushes (if they have them), deodorant (if it's available). After ten minutes, all the razors for the day are gone. The sign says "Razors not available." "Oh man, I need a shave!" One of the senior staff comes around to see if people want foot care. Foot bath and clean socks. People also line up for showers at nine a.m.

Later on, people go back outside. They go through their usual day. Many go to get signed in for a bed at one of the few ("many", as the government claims) shelters for the night. Many sleep outdoors. Tent City moves around from park to park, and people sleep that way too.

Night falls. Time passes. Next day comes. You do it all over again. It's a neverending cycle of poverty.

"Who's got a rig?" ⊕

Arthur Weiss lives in the Downtown Eastside.



BCPWA Advocacy gets results!

The BCPWA Society's Advocacy Program continues to work hard to secure funds and benefits for HIV+ individuals. The income secured for October and November 2003 is:

- **$62,499.41 in debt forgiveness.**
- **$58,173.29 in housing, health benefits, dental and long-term disability benefits.**
- **$24,845.00 in Monthly Nutritional Supplement Benefits.**
- **$376,162.78 into members' hands for healthcare needs, from grandfathered Schedule C benefits.**

Funding crunch

BC Centre for Excellence drug program at risk

by Rob Gair

The BC Centre for Excellence in HIV/AIDS (BCCfE) at St. Paul's Hospital in Vancouver is not just a world-class AIDS research facility. It also provides specialized medical care. One of the BCCfE's chief functions is the distribution and monitoring of antiretroviral medications to British Columbians living with HIV. Generally, individuals receive medications free of charge, and they are enrolled into a database from which their progress is monitored. The provincial Ministry of Health provides funding for the drug treatment program.

Recently, however, the ministry has indicated that funding for this vital program may be frozen as part of an overall limit on healthcare spending.

In the mid-1990s, triple-drug therapy dramatically decreased progression to AIDS. This therapy improved quality of life for individuals living with HIV and decreased the overall financial burden on the healthcare system. At this time, many individuals were relatively naïve to antiretrovirals and were in need of effective drug treatment. Hence, the early years saw a steady rise in enrolled patients with an equally steady rise in the drug budget.

In the early 2000s, enrollment levelled off for several reasons. Most people who needed drug therapy were already enrolled, and many were opting for treatment interruptions. As well, newly diagnosed individuals were moving towards treatment deferral. This choice was good news for ministry officials who looking for ways to contain costs. However, recent developments on various fronts have brought pressure on the drug budget. Additional money will be required to maintain current standards.

One of the challenges is an anticipated surge in new patients.

Approximately 3000 people are currently receiving antiretroviral medications in BC. The program is growing by about 10 patients/month (4 percent per year), but a combination of factors will lead to a projected doubling of the rate of growth in the next few years. Most significant is the estimated 3000 HIV-positive injection drug users, only 10 percent of whom are currently receiving treatment, and all of whom also have hepatitis C. Most have been HIV-positive for a number of years and will soon need drug treatment to avoid lengthy hospital stays. Another significant group is people who were able to defer treatment under newly established guidelines in the early 2000s. They will need to start treatment in the next few years, as will most of those who sought treatment interruptions. Aboriginal peoples and other groups who are currently undertreated will also need increased access.

In addition to increased patient growth, the cost of newly approved medications is rising dramatically.

In addition to increased patient growth, the cost of newly approved medications is rising dramatically. New patients typically respond to older drugs at a cost of approximately $1000 per month. This sum is relatively small in light of the growing number of long-term patients who typically require newer medications and more complex drug regimens. Costs for these individuals often approach $2000 per month or more. The current average annual cost per "salvage" patient is $17,000 and a new drug such as enfuvirtide (Fuzeon; T-20) will cost an additional $30,000 per person per year. To add to the problem, drug companies have indicated they are no longer willing to provide cheaper prices to Canadians because of cross-border shopping by Americans.

The current success of the drug treatment program at the BCCfE is under funding pressure due to an ongoing influx of new patients, combined with a dramatic rise in drug costs. If the BC Ministry of Health, through PharmaCare, does not increase funding annually at a rate sufficient to keep pace with these growing needs, something will have to give. A significant increase in spending will be required to maintain current standards of patient care and reduce negative impacts on the healthcare system.

The BC government has apparently agreed to ante up the additional funds needed to keep the program afloat to March 31, 2004. The future beyond that date remains uncertain. ⊕

Rob Gair is a pharmacist at the BC Drug & Poison Information Centre.

HIV and mental illness can be a double stigma

by R. Paul Kerston

Something as small as a change in sleep habits, something as minor as an inability to concentrate. These simple signs of depression are very common, and most people experience them more than once. Depression can make you more prone to behaviours that can lead to HIV infection and to treatment non-adherence, further risky sexual behaviours, dangerous drug abuse, and re-infection. It can also make day-to-day living difficult, given the complexity of issues such as housing, income, and medication. This heightened vulnerability to HIV because of mental illness is particularly important to understand.

continued on next page

Mental illness encompasses a range of disorders, including various forms of depression, bipolar disorders, schizophrenia, and psychoses. Some mental issues are relatively minor. However, others can be exacerbated by our body's preparedness to cope and by our skills in dealing with them.

Stress is often the culprit that grinds our minds to a halt and makes us unable to function. It is a normal part of everyday life, but not all of us learn how best to cope with it. If the stress of everyday decisions is further exacerbated by such factors as living with HIV, treatment regimens, and mental illness, we may need to learn coping skills and to get assistance from medications or herbal remedies. However, pills alone are often not enough. Counselling is often necessary.

Depression, the most common mental illness, has many triggers among HIV-positive persons, including: fear of disclosure, insufficient income to socialize, social stigmatization, work-related issues, and housing difficulties. With or without HIV, when depression makes you feel alone—despite being physically present with others—your self-confidence and self-esteem may falter. More than many other issues, depression can cause people to seek love or solace in all the wrong places, leading to risky behaviours, drug abuse, and, ultimately, HIV infection.

A combination of factors

Depression is a cycle in which people become trapped. Low self-esteem can be a threat to your well-being. People can become easily overwhelmed by any situation, especially such a complex one as living with HIV/AIDS, and their emotions can spin out of control. The combined stress of mental illness, HIV, and coping with day-to-day needs can have a cascading effect, taking the floor right out from underneath people and leaving them at their most vulnerable, whether or not they realize it.

Many individuals feel low from time to time. Life's surprises can make anyone feel as if the wind has been knocked out of them. At times, all of us feel less ready to tackle what life throws our way. Feeling a little bit low, on occasion, is commonplace. However, some people feel lower more often or are not able to function properly. Others appear more manic, bouncing between lows and highs to such a degree that a diagnosis of bipolar disorder can prove helpful in treating the causes.

Similarly, with schizophrenia the mind can sometimes wander in such a manner that it feels beyond one's control. This sense of loss of control can disable people with mental illness. It can be especially disabling when people are also diagnosed with HIV. Coping skills need to be learned. Medication may be necessary.

Diagnosing mental illness

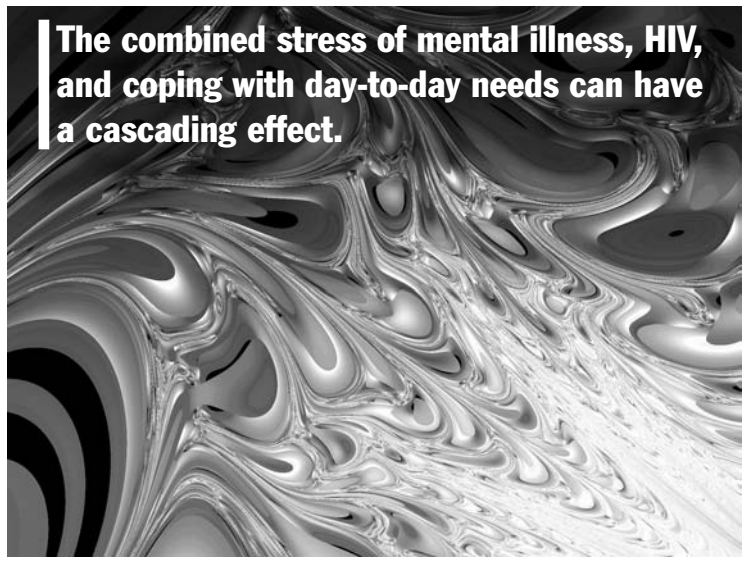
Although checklists are available to help you assess your mental state, these tools don't work for everybody. It is always advisable to consult a professional. Some common warning signs may include sleeplessness, lack of concentration, or unusual hyperactivity. Other warning signs include feeling lost, seeming unable to function, and being unable to imagine the future. Jim, a speaker at a Vancouver Carnegie Centre forum in October, says that he was initially in denial regarding his HIV illness and that he masked his depression, hiding it from his co-workers and his friends. As he explained, you might be the life of the party, but underneath that façade you're suffering from depression.

Once you have determined that you may have a mental illness, you then must be diagnosed and seek information and viable treatment options. Treatment by willpower alone is often not enough; you will need help to overcome your difficulties. You need to know that change is possible and that you are not alone.

Healthcare professionals must distinguish between depression and demoralization. According to Dr. Andrew F. Angelino of Johns Hopkins AIDS Psychiatric Services, episodes of major depression at his clinic recur in 75 percent of people within a year. However, feeling demoralized because of recent events, such as a work-related issue, often does not recur. Dr. Angelino also notes that depression can have a gradual onset or a precipitating event such as diagnosis of HIV.

Getting treatment in Vancouver

In the Vancouver area, HIV-positive persons with mental illnesses do have access to treatment and care. At the St. Paul's Hospital Immunodeficiency Clinic, social workers offer both individual and group counselling. Other access points in the community are available through the Vancouver Coastal Health Authority, including clinics in Strathcona, the Downtown Eastside, and the West End. The BCPWA Society also offers a support counselling service.



People may want to consider alternative therapies such as herbal remedies. Vancouver naturopath Dr. Aaron Hoo cautions that individuals must inform their general practitioner of their alternative care prescriptions and advise their naturopath about their HIV regimens to avoid possible adverse drug reactions.

If the situation is urgent, a crisis line and a vehicle (Car 87) with trained personnel are available. A residential care facility called Venture helps people in crisis.

Lack of provincial support

British Columbia's Medical Services Plan (MSP) does not cover most mental health services. For example, social workers and psychologists are only covered when practicing through a hospital or funded agency. Private practitioners are not covered at all. As a result, the dedicated mental health professionals at our health facilities are feeling the pressure of growing caseloads, making their work more complicated. To address the often cyclic nature of mental illnesses such as depression, particularly among HIV-positive persons, the local health authority may need to address its priorities and fund additional positions to help deal with this burden. Reductions to MSP-covered mental health services should be reconsidered.

BC's Medical Services Plan does not cover most mental health services. Private practitioners are not covered at all.

The St. Paul's Hospital Immunodeficiency Clinic has two social workers. They provide individual counselling and a support group that has been meeting weekly for over ten years. One of the workers, Mary Petty, notes that the evolution of the group seems to have paralleled groups elsewhere. The people in the group help one another by showing they are not alone and by sharing experiences and information. Though the group uses a peer model for discussion, the social workers are present to ensure that guiding hands are always available. Additional mental health professionals are available through outpatient psychiatry at St. Paul's.

According to Ralph Buckley, the director of the Strathcona Mental Health Team, the patient population for mental health services in that neighbourhood is composed primarily of injection drug users, but all individuals are welcome. For persons who are dealing with HIV regimens and have any difficulties with adherence, Strathcona works with the local Maximally Assisted Therapy (MAT) program. Buckley notes that although public awareness of mental health issues has grown, so too has the availability of cheaper and more lethal street drugs.

Both community health facilities and St. Paul's services are covered by MSP. That's especially important because when all else seems to be caving in, it's good to know that help is available at no direct cost to you.

The stigma of a dual diagnosis

A key topic that surfaces in both individual and group therapy is the range of barriers that leaves HIV-positive people living with mental illness feeling so vulnerable. A common barrier is lack of self-confidence, feeling unable to fit in socially or at work. Depression can make you feel as if your social connections have been cut, increasing your loneliness. HIV can do the same thing. In combination, living with mental illness and HIV can feel more stigmatizing than many people can handle.

Talking about these issues with a social worker, a counsellor, or other persons in the same situation can be very helpful. These feelings don't indicate a character flaw. They are common issues that can be dealt with. It's important not to let the expectations of others influence your own view of yourself.

Once you have successfully conquered a depressive episode, take heart in your developing coping skills. These skills will be extremely important in breaking the vicious cycle of illness.

Many people say that in learning to live with HIV and mental illness, they've learned to live in the present, one day at a time. It sounds so basic, but many of us could profit from adopting a similar mindset, and the result could be a healthier community. There is hope. ⊕

Places to call in Vancouver:

West End Mental Health Team:
604.687.7994

Strathcona Mental Health Team:
604.253.4401

St. Paul's Hospital Immunodeficiency Clinic:
604.806.8060

Vancouver Community Mental Health Services General Enquiries:
604.874.7626

R. Paul Kerston is a researcher with the BCPWA Society's Treatment Information Program.

Biased in Bangkok

Fighting for support for injection drug users in Thailand

by Tom Kerr

Thailand has been remarkably successful in increasing condom use and reducing HIV infection among sex workers and their customers. In fact, Thailand's "100% Condom" program is often heralded as the best example of an effective HIV prevention effort in the developing world. However, what most people do not know is that the first wave of HIV infection in Thailand actually occurred among injection drug users (IDUs) over 15 years ago, and since that time the Thai government has done absolutely nothing to address the needs of this population.

The epidemic spread of HIV infection among IDUs in Thailand was first observed in Bangkok in 1988. Within six months, HIV prevalence among IDUs rose from 2 to 40 percent. In 2000, sentinel surveillance from 39 sites in the north, central, and southern regions of Thailand revealed HIV prevalence rates among IDUs between 40 and 60 percent. Although HIV prevalence among other at-risk populations peaked between 1994 and 1996 and has declined steadily and substantially since then, HIV prevalence rates among Thai IDUs in 1999 were higher than they were ten years before.

In 1990, the prime minister of Thailand made HIV control a national policy. Despite considerable investment and political commitment devoted to addressing HIV/AIDS, the Thai government has not implemented measures that address the specific HIV prevention, treatment, and care needs of IDUs. Currently, none of the national prevention budget is allocated for the prevention of HIV infection among IDUs. Despite the overwhelming scientific evidence supporting the efficacy of interventions such as syringe exchange, methadone maintenance, and outreach in reducing HIV incidence among IDUs, harm reduction programs have not been implemented.

Last year, the situation for Thai IDUs got even worse. In February 2003, in a futile attempt to make Thailand "drug free," the Thai prime minister announced a large-scale crackdown on the country's drug users. Over a three-month period, an estimated 4000 to 5000 drug users were executed without any form of judicial process, and approximately 50,000 drug users, many of whom were subjected to mandatory HIV testing, were forced into military treatment camps. Like other police crackdowns that aim to arrest high-level dealers, this campaign did little other than target individuals who use drugs. Despite considerable international pressure

from the United Nations and human rights organizations, the war against drug users in Thailand quietly continues.

Fortunately, a significant and positive development occurred during October 2003. With support from the Canadian HIV/AIDS Legal Network and the BC Centre for Excellence in HIV/AIDS, the newly formed Thai Drug Users' Network (TDN) submitted a proposal to the Global Fund to Fight AIDS, Tuberculosis, and Malaria. The proposal, which focused on capacity building, outreach, and HIV prevention and treatment for IDUs, was submitted without the normally required government approval. In a

In 1999, HIV prevalence rates among Thai IDUs were higher than they were ten years before.

precedent-setting decision, the Global Fund board approved the US$1.4 million proposal, and in doing so appear to have created a new exemption category for applicants who experience severe forms of repression and marginalization within their countries. This money is the first HIV-specific funding dedicated for IDUs in Thailand.

The neglect and abuse of drug users in Thailand continues. It is generally supported by a dominant public attitude that can only be described as discriminatory in the extreme. However, the persistence of a group of courageous Thai IDUs, supported by their international partners, has fostered a new sense of optimism. Let's hope this is just the beginning of better times for IDUs in Thailand. ⊕

Thomas Kerr is director of health research and policy at the Canadian HIV/AIDS Legal Network and a research associate at the BC Centre for Excellence in HIV/AIDS.

Let's talk about it!

Planting a bug in your ear

by Phillip Banks

There was a bit of a stir in Vancouver's gay community recently following the screening of a controversial documentary from San Francisco about gift giving and bug chasing. Last August, the Vancouver Queer Film & Video Festival presented the documentary *The Gift* followed by a panel discussion addressing the intentional infection of a consenting partner (gift giving) and intentionally seeking HIV infection (bug chasing). The discussion was heated. Some folks were upset by the phenomenon as depicted in the film. Other folks wanted explanations for what they see as an increase in the practice of bareback sex in the gay community.

A big focus of people's anger seemed to be attempts made by some panelists to distinguish barebacking from gift giving and bug chasing. Many people saw this as an attempt to excuse people's irresponsible behaviour. Anyone picking up an *Xtra West* or other community papers in the weeks following the screening would have seen that the issue was not going to just go away. A kind of momentum seemed to build with more and more people entering the discussion.

It's hard for people to understand why someone would want to get infected with HIV by intentionally seeking out an infected partner to have unprotected sex. In the film, one guy explained it as a way of making connections with other gay men and creating an identity in a community that felt cold and isolating. Another guy saw getting infected as a way of putting an end to the stress caused by feeling that it was going to happen eventually. So why not just get it over with?

Are these attitudes and perceptions due to HIV prevention going off the rails? Are they due to a failure of the gay community to provide support and guidance to our most vulnerable? Are HIV-positive guys to blame for infecting HIV-negative guys? Are negative guys to blame for not taking care of themselves? Who is responsible for these guys getting infected? Who is going to stop the madness?

I don't presume to have the answers to these questions. I want to say that talking about these questions is important and that by talking about them rather than ignoring them we stand a chance of stemming the tide of new infections. But I think we have to do more than just talk.

We have to demand more resources for gay men's HIV prevention. We need to demand more resources for gay men's community health initiatives. We have to look beyond HIV to a future without HIV. We need to imagine that there will be a time when gay men and others will be able to grow up without the sense of the inevitability of HIV infection being hard wired into our brains. We need to take responsibility for ourselves and, if we want to call ourselves community, be responsible to others. We need to make better choices in the face of a terrible illness. We may need to make sacrifices. What do we want our gay communities to look like in twenty years?

Talking is a great place to start. But let's make sure we don't make talk look cheap. ⊕

Phillip Banks is the coordinator of Gayway gay men's health programs at AIDS Vancouver.

The other side of science

Understanding community-based research

by Francisco Ibáñez-Carrasco

A young gay man repeatedly goes on a binge of raves, crystal, and barebacking. Reckless behaviour, you're probably thinking. You probably wouldn't consider it research. An aboriginal HIV-positive woman on anti-HIV medications gets pregnant because she has seen other positive women having healthy babies. Is this action irresponsible or the reasonable outcome of her qualitative observations?

If you think that academic research cannot be this reckless, think again. Take, for example, the case of the Tuskegee syphilis research scandal in the US, which had a president apologizing to the nation for government scientists' cruel deception and manipulation of human test subjects. Some of us argue that as long as a person engages critically and ethically with his or her world, that person is a researcher advancing knowledge. In community-based research (CBR), we begin and end with the person and her or his engagement with the world. We place ourselves at the other side of science.

Research, much like literature, is about telling scientific stories in numbers and statements. CBR investigates and evaluates the myriad of issues around health, illness, and HIV/AIDS. It engages our world by combining missionary theoretical positions, such as basic science and epidemiology, with unorthodox positions, such as feminism, anti-racism, queer studies, and environmentalism.

CBR combines science with unorthodox positions such as feminism, anti-racism, queer studies, and environmentalism.

Gradually, institutions are attending to needs for collaborative work that links findings—say, why women are not always able to use the female condom—with everyday life contexts in which gender, politics, business, and even faith play a role. CBR involves scientific methods, political views, and even business aspects because it is often carried out on our flesh-blood-and-bones bodies by, for example, pharmaceutical companies. CBR seeks to change old institutional habits of doing research that seem benign because they do nothing for people. Health Canada's funding of research technical assistants across Canada can help put some of these ideas in motion with community-based organizations that include HIV/AIDS work.

In CBR, the subject becomes the agent. What we already know is often put in a scientific perspective and language, and this process generates new knowledge. We can research with young men who do drugs and have bareback sex to understand their situations and find ways of reducing physical and emotional harm. We can provide evidence-based support to HIV-positive aboriginal mothers.

Partnerships are crucial to CBR. We don't have to love one another, but we must work together. PWAs offer sophisticated understandings of lived experience, university folks provide the scientific frameworks, and the combination creates the reliability, validity, and credibility wanted by all those involved: PWAs, funders, health authorities, and even private companies, such as insurers.

Not only must it be credible, CBR must be applicable. The transference of knowledge into policy and programming helps frontline workers apply research. They see that it is useful. Intellectuals and researchers stop whining about frontline workers' knee-jerk reaction to AIDS issues.

Our CBR capacity building program, guided by a provincial advisory committee that includes frontline workers, volunteers, and university-based researchers, has a workplan. That plan includes serving smaller organizations first and charting our skills, experience, and needs for community-based research in BC. Next year, it will deliver workshops across the province on the key aspects of research, such as reading epidemiological tracts and designing surveys. ⊕

Francisco Ibáñez-Carrasco is a BCPWA Society research technical assistant. As a Latino immigrant, once a youth with HIV and now a dinosaur in the movement, he has seen the other side of science.

Talk ain't so cheap

Supreme Court ruling underlines implications of non–disclosure

by Raymond Campeau

For better or worse, gay male culture has a heavily skewed perspective on sex. Gay men feel a certain entitlement when it comes to accessing uncomplicated, uninhibited sexual gratification. No wonder then that a deluge of wordy articles have appeared describing the most recent Supreme Court of Canada decision regarding disclosure of HIV status to sexual partners. Fun, easy sex is getting increasingly complicated.

On September 18, 2003, the Supreme Court released a unanimous decision in R. v. Williams. The case builds on the 1998 Supreme Court decision of R. v Cuerrier, whereby the court made it undeniably clear that not disclosing your HIV status before unprotected vaginal or anal sex is fraud. This fraud, in turn, makes your sexual partner's consent invalid; without proper consent, your sex act becomes an assault. R. v Williams is the first case since then in which the highest court in the land discussed criminal liability for HIV exposure. The subtle difference in the two cases concerns whether the charge should be attempted aggravated assault or simply assault.

The Supreme Court of Canada seems to have burdened all people with a required dialogue before engaging in sex.

The Supreme Court seems to have burdened all people with a required dialogue before engaging in sex. We all must now disclose personal aspects of ourselves before engaging in unprotected sex if we want to avoid criminal prosecution.

If you are HIV-positive and do not disclose your status before having unprotected sex, you can be charged with assault or aggravated assault. You do not actually have to infect someone. You can be charged simply for putting another person at significant risk.

Legally required disclosure is leading to heated and interesting debate. At issue is the feeling among some PWAs that types of sexual behaviour are being criminalized. For many, the easiest solution is not to disclose and deny when required. Many HIV-negative men and some HIV-positive men feel that it is incumbent upon HIV-positive people to disclose and that they are cowards if they don't.

No cut and dried protocol exists for sex, just lots of used and unused rubbers. Some people fully disclose and leave it to the partner to decide what they want to do. Some feel more comfortable not disclosing and having safer sex. Others feel that unprotected sex is fine if the partner does not request protection. It is this last scenario where trouble may lie and litigation may start.

It is unlikely that the courts will be monitoring bathhouse etiquette. But what about two men who date a few times, then find themselves having regular sex, sometimes unprotected?

In the heat of the moment, it is unlikely that any of us are thinking about the guidance and wisdom of the Supreme Court of Canada. Perhaps we need to develop strategies and options to respond comfortably when we are presented with a situation too good to resist.

The courts will apply the law equally to both gay and straight people. Gay culture may be different from straight culture when it comes to partnerships and sex, but the law does not discriminate. Never has it been more important to take that burden of dialogue and use it to protect yourself.

If you are HIV-positive, you really need to assess your feelings about unprotected sex because it could come back and bite you in the ass.

Gay men will have many different opinions about what works for them as individuals when deciding whether or not to disclose their HIV-status. At least one option is dialogue. The courts cannot mandate it, nor can the government legislate it, but it is definitely something to consider. ⊕

Raymond Campeau is currently an assistant to the Treatment Information Program and Advocacy Department at the BCPWA Society.

TREATMENT INFORMATION PROGRAM MANDATE & DISCLAIMER

In accordance with our mandate to provide support activities and facilities for members for the purpose of self-help and self-care, the BCPWA Society operates a Treatment Information Program to make available to members up-to-date research and information on treatments, therapies, tests, clinical trials, and medical models associated with AIDS and HIV-related conditions. The intent of this project is to make available to members information they can access as they choose to become knowledgeable partners with their physicians and medical care team in making decisions to promote their health.

The Treatment Information Program endeavors to provide all research and information to members without judgement or prejudice. The program does not recommend, advocate, or endorse the use of any particular treatment or therapy provided as information. The Board, staff, and volunteers of the BCPWA Society do not accept the risk of, nor the responsibliity for, damages, costs, or consequences of any kind which may arise or result from the use of information disseminated through this program. Persons using the information provided do so by their own decisions and hold the Society's Board, staff, and volunteers harmless. Accepting information from this program is deemed to be accepting the terms of this disclaimer.

Nutrition in a can

There are alternatives to commercially-made nutritional supplements

by Ágnes P. Kalmár, RDN

Many people living with HIV/AIDS have a hard time getting adequate nutrition on a daily basis because of poor appetite, taste changes, and inability to eat enough to maintain or gain weight. Commercially made nutritional supplements such as Ensure and Boost have helped many people get through periods when getting adequate nutrition is difficult. The manufacturers of these supplements have persuaded many people that they can't live without them.

Inside the can

A close look at the ingredient lists of these supplements reveals that the main ingredients are water, corn syrup, sugar, oil, milk protein, soy protein, and a small amount of vitamins and minerals.

These ingredients don't sound very tasty, and indeed manufacturers need to do a lot of processing before they can turn this mixture into a shelf-stable drinkable supplement. In order to meet your daily requirements for vitamins and minerals, you would need to drink four cans of supplement. To meet your daily requirements for energy, you would need to drink eight to ten cans per day, which would provide 2000–2500 kcal. Most people don't drink that much. Taking a multivitamin and mineral pill daily will give you the same vitamins/minerals without having to drink four cans of supplement.

There is truly nothing miraculous about nutritional supplements. They can be very expensive, and it is easy to find substitutes.

Do it yourself

You can make your own shakes and take a multivitamin and mineral pill daily. All you need is a blender. It is much cheaper than nutritional supplements, and you can experiment with many more flavours.

continued on next page

A basic recipe

- Always start your milkshakes with whole milk (3.25% M.F.) unless you have been told to avoid excess fat, in which case use skim milk, 1% milk, or yoghurt.
- Add some skim milk powder or protein powder for extra protein (1–3 tsp/cup).
- If you are lactose intolerant, use soy milk and soft tofu or Lactaid milk.
- Add some of the following foods: peanut butter, jams, jellies, syrups, ice cream, yoghurt, pudding, fruit, frozen juice concentrate, vanilla, or ice cubes. The possibilities are endless. Adding extra flavourings will mask unpleasant tastes. Be creative!
- Blend it well and serve it immediately. If some is left over, you may be able to refrigerate it and have it later, but it's best to consume your shake fresh. If you have Popsicle holders, you can freeze the leftovers and have a high-protein frozen snack.

If you want to add eggs for extra protein, make sure they are pasteurized. Just cracking an egg is not a good idea because it may be contaminated with salmonella.

You may also need to eat high-calorie, high-protein foods with your milkshakes. High-calorie foods include cheese, nuts, dried fruit, butter, margarine, ice cream, gravy, whipping cream, sour cream, and mayonnaise. High-protein foods include cheese, cottage cheese, yoghurt, nuts, eggs, tofu, lentils and beans, meats, and peanut butter.

When to use nutritional supplements

Although nutritional supplements can easily be substituted with homemade milkshakes and a vitamin/mineral pill, sometimes it is appropriate to use commercially made supplements. Not everyone has access to a fridge and a blender, essential tools for making your own shakes and storing them properly. If you are too weak or tired to do anything, preparing a shake may require too much of your energy. People may also enjoy the convenience of commercial supplements when they are away from home because they don't require preparation and can be carried around for a timely snack.

If you have the money and you like the convenience of simply opening a can, nutritional supplements may be a good choice for you. Other brands equivalent to Ensure and Boost, such as Resource, are now on the market. Some stores now carry their own generic brand of nutritional supplements that are cheaper than national brands. For people with diabetes and/or insulin resistance, or those who need to watch their sugar intake because of high triglyceride levels, lower sugar formulations, such as Glucerna, Resource Diabetic, and Choice, are available, but these are expensive formulations. Talk to your dietitian about other options.

The Ministry of Human Resources' Ensure program

At one time, if you were on income assistance, you could just ask your doctor or dietitian for Ensure. However, new regulations mean that the Ministry of Human Resources will not authorize any extra funds for Ensure for people who are on income assistance and receive the Monthly Nutritional Supplement allowance (an extra $225 for food, water, and vitamins). This extra money is supposed to cover nutritional supplement costs as well. If you are on income assistance, but you do not receive the Monthly Nutritional Supplement allowance, then you are still eligible to get Ensure by prescription. Talk to your dietitian about your options.

Quick milkshake recipes

These shakes will provide the same or more calories and protein as your average nutritional supplement.

Yoghurt cooler

1 cup of milk
2 tbsp of skim milk powder
1 small container of fruit yoghurt
Add a piece of toast and you have a balanced meal.

Mocha milk cooler

1 cup of chocolate milk
1 large scoop of coffee ice cream or cappuccino yoghurt
15 mL chocolate syrup
5 mL instant coffee
2 tbsp of skim milk powder
Add half a bagel and a piece of fruit for a balanced meal.

Banana honey milkshake

1 banana
1 cup of milk
2 tbsp of skim milk powder
1 tbsp of honey
1 scoop of vanilla ice cream
Sprinkle with cinnamon before serving.

Peanut butter and jelly milkshake

1 cup of milk
1/4 cup of peanut butter
1/2 cup of chocolate ice cream
3 tbsp of jelly
1 tsp of vanilla extract

For more ideas on milkshakes and how to increase your calorie intake, contact your dietitian. And remember, good nutrition is not locked in a can! ⊕

Ágnes P. Kalmár, RDN, works as dietitian in a variety of areas of BC Children's and Women's Hospital in Vancouver and often fills in for the Oak Tree Clinic dietitian.

Novel therapies in the pipeline

New HIV drugs work outside the cell

by Tom Mountford

Within the existing classes of drugs used to stop HIV replication, creating a long-lasting cocktail is complicated by the emergence of viral mutations, life-threatening/altering adverse events, and the rapid rise of new multi-drug resistant infections. New treatment approaches are long overdue.

Drugs that work inside the cell may be efficiently neutralized by the cell's self-defence mechanisms, which sense toxins and eject them. Antiretroviral therapies that work outside the cell may circumvent this problem and have little or no potential for cross-resistance with current drug regimens.

Last summer, the Treatment Action Group identified some novel drugs that have found new, vulnerable targets to attack and defeat HIV. These drugs block entry to the cell.

T1249 is an entry inhibitor, similar to enfuvirtide (T-20), but it binds to gp41, a molecule on the virus's surface that changes its shape in a specific way to allow viral fusion just downstream of enfuvirtide's binding site. It has shown a significant reduction in viral load in patients with enfuvirtide-resistant strains of HIV. The only side effects were some swelling or redness at injection sites. Phase II studies have begun in PWAs to identify common, short-term side effects and risks.

Pro-542 is an attachment inhibitor that prevents HIV entry by binding and neutralizing one of the proteins (gp120) sticking out from the surface of the virus used to engage with CD4 receptors on the surface of lymphocytes. It appears to be well tolerated, with good dose-dependent viral load reductions. It may be a valuable prophylaxis against HIV infection in perinatal treatment or after occupational or sexual exposure. In trials, infectious virus could not be recovered for more than 72 hours after a single infusion. Phase II trials are underway in the US.

TNX-355 is another entry inhibitor that binds to the side of the CD4 receptor, preventing viral entrance without interfering with its regular function as a chemokine receptor. Attachment to CD4 cells was noted up to 27 days after treatment. Significant viral load reductions were seen as late as 21 days after a single dose, raising the possibility of dosing once every three weeks. Higher doses of the antibody caused an immediate increase in CD4 count. It was well tolerated with no noted side effects. Phase II trials are underway.

SCH-C blocks the HIV-1 co-receptor CCR5 and is approximately as potent as zidovudine (Retrovir, formerly AZT). An oral drug, it is easily absorbed with effective amounts remaining in the body for over 24 hours in initial human testing. Synergistic interactions were seen within all current HAART classes as well as with enfuvirtide (T-20), raising the possibility of successful combination for treatment of multi-drug resistant infections. Possible side effects include disturbance of cardiac rhythm. SCH-D is also being studied. It is better absorbed and ten times more potent in the lab than SCH-C.

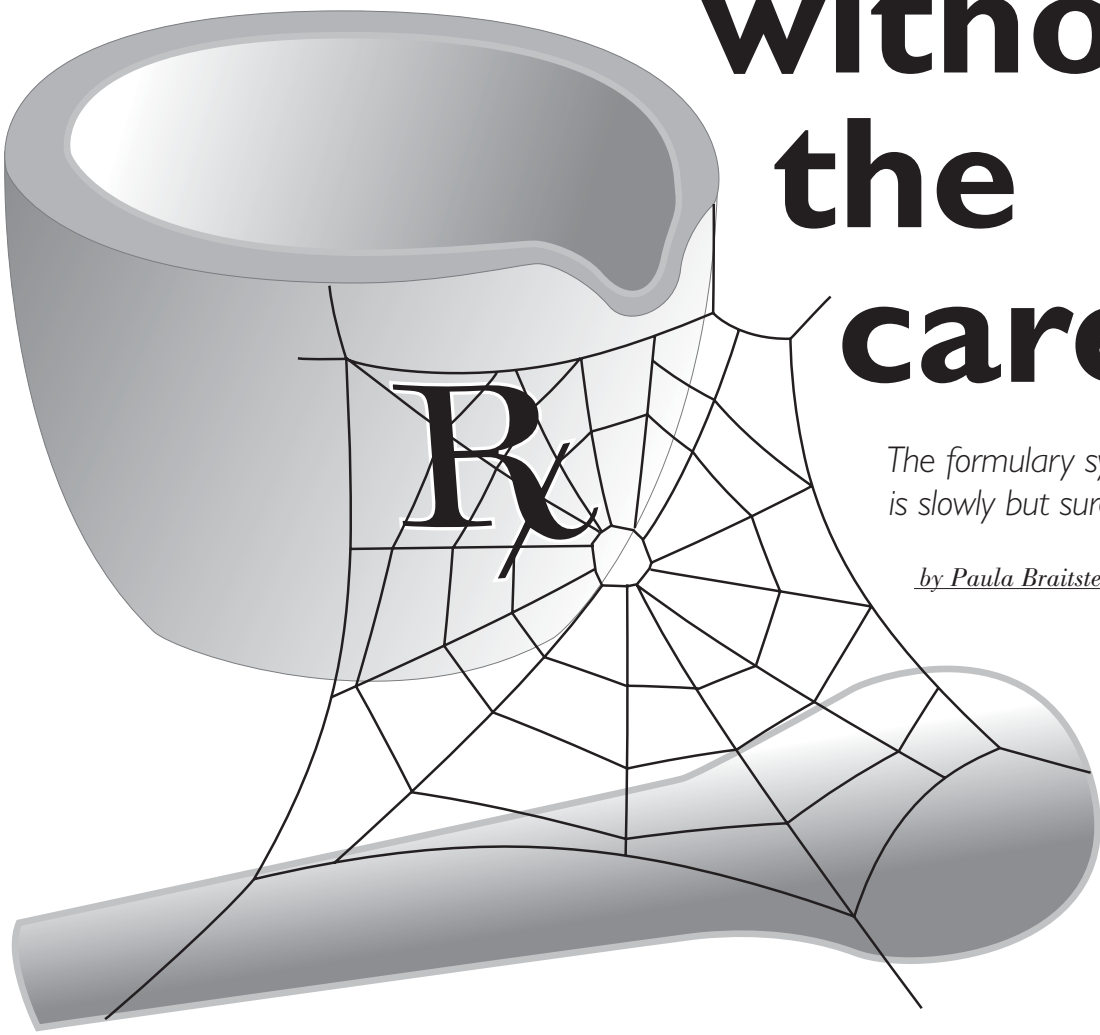
UK-427,857 interferes with viral entry by way of the CCR5 receptor, but not CXCR4, which is generally viewed to be used by a more aggressive form of the virus and is associated with advanced disease progression. A small study of patients with CCR5-tropic virus demonstrated few adverse events, significant viral load reductions, and no chemokine interference. It was also active against drug-resistant HIV.

Back inside the cell, researchers are targeting a little understood enzyme, integrase. It plays a vital role in HIV replication by inserting HIV's genes into a cell's normal DNA. One integrase inhibitor that showed promise is **S-1360**, which has synergy with all available HAART drugs and potency on par with lamivudine. It is well tolerated and can be taken once a day. Phase II studies are underway.

Researchers found another integrase inhibitor **(L-870,810)** much superior to S-1360 in lab studies. Phase II studies began last fall. Despite conflicting reports of cross-resistance between the two integrase inhibitors, it is widely believed that any new drugs will be absolutely critical for salvage therapy and new classes must be fully investigated. ⊕

Tom Mountford is a volunteer with the BCPWA Society's Treatment Information Program.

PharmaCare without the care



The formulary system is slowly but surely eroding

by Paula Braitstein

I have always found the issue of drug formularies a bit mysterious. It took me years to figure out what a formulary was, and even then it was mostly by osmosis. Lest you should be misled into thinking that as Canadians we have a truly universal healthcare system, I will share my understanding of formularies and how the formulary system is slowly but surely eroding.

A formulary is the list of drugs that your provincial government will pay for, in part or in whole. The selection of medications onto a formulary is based, in theory, on an objective evaluation of each medication's therapeutic merits, safety, and cost. Because health falls under provincial jurisdiction, all formularies are provincial, and the drugs listed can vary significantly from province to province. In addition, there are six federal formulary programs (Non-Insured Health Benefits, Veterans, etc.).

Approximately one in five Canadians is covered under a provincial drug benefit plan to help pay for their drugs. (Some provinces have user fees or deductibles.) Estimates suggest that provincial drug plans account for 30–40 percent of all prescription drug sales in Canada. Seniors and people receiving social assistance represent 25 percent of people needing public drug coverage, but they account for 50 percent of drug utilization in Canada.

Most formularies have two categories: full listing (a doctor can prescribe the drug as necessary and the province will help pay for it) and restricted listing (a doctor must get special, written approval from the province that the drug will be covered before prescribing it). Pegetron, a new and more effective treatment for hepatitis C, is an example of a drug that technically has been placed on the formulary, but its access criteria is so restrictive that the vast majority of people who need it won't ever get it.

Fewer new drugs listed in BC

Traditionally, once a company got approval from Health Canada to market its drug in Canada, it would apply to each public drug plan (that is, formulary) for coverage. In recent years, several disturbing trends have surfaced regarding the listing of drugs on formularies. In 1999, seventy-nine percent of new products launched in Canada were listed on formularies. In British Columbia, which is among the worst for putting drugs on the formulary (Quebec is the best), 16 of 52 drugs (31 percent) were listed in 2000-2001, and only 1 of 27 drugs (4 percent) was listed in 2003. It is probably not a coincidence that the Liberal BC government severely slashed the PharmaCare budget (and staff) in 2001. It is also probably no coincidence that they recently added a new step in the formulary process, a step that in its current format can only reduce access to new medicines for consumers.

Our healthcare system faces very real isssues related to pharmaceutical expenditures. Health Canada reported that in 1998 pharmaceutical drugs accounted for 15.6 percent of total health expenditures. The report from the Federal/Provincial/Territorial Pharmaceutical Issues Committee found that among the six provincial drug plans studied, a 44 percent increase in pharmaceutical expenditures occurred between 1990 and 1997. An analysis of the BC PharmaCare system found that by 1997, drugs introduced since 1990 accounted for 57 percent of PharmaCare spending.

On September 6, 2002, the federal, provincial, and territorial health ministers announced the creation of a common process for reviewing new drugs for potential coverage by public drug benefit plans (i.e. formularies). Currently, a single process is conducted by Health Canada to review drugs for safety and efficacy prior to licensing them for use in Canada. However, each province or territory conducts its own review to determine which drugs will be listed—that is, paid for—in the public drug plans. Under the Common Drug Review (CDR), the Canadian Coordinating Office for Health Technology Assessment (CCOHTA) will be responsible for conducting all reviews and providing recommendations as to which drugs should be listed for federal, provincial, and territorial drug plans, with the present exception of Quebec.

A new step in the formulary process can only reduce access to new medicines for consumers.

Listing drugs under CDR

The CDR is a three-stage process for deciding whether a new drug will be listed:

1. The CCOHTA will review a new drug either in-house or through external contractors. The review will be based on its clinical benefits relative to other drugs or treatments and its cost-effectiveness (for which CCHOTA has yet to define their criteria).
2. The Canadian Expert Drug Advisory Committee (CEDAC), using the clinical and cost-effectiveness information, will then go through a second process to decide whether to recommend the drug for inclusion in drug benefit plans.
3. Each federal, provincial, and territorial plan will then go through its own process to decide whether it will list the drug, not list the drug, or list it with restrictions. Some provinces have already said that they will re-review all the submissions they receive, meaning an additional six months minimum to the listing process—if it's approved. However, provinces will only review submissions that were favourably recommended by CEDAC. Those not recommended by CEDAC will be stopped in their tracks. In other words, "no" from CEDAC means "no" from the provinces, but "yes" from CEDAC only means "maybe."

The CDR has a number of potential benefits. It could reduce duplication of effort in reviewing submissions for listing drugs on public formularies and provide consistent quality review of drugs. Thus, it could improve timely access to new medicines and ensure that drugs with therapeutic value are available to people who need them. Moreover, the CDR could reduce the inequities in access that currently exist from province to province.

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The downside of CDR

Nevertheless, this system presents risks to healthcare consumers. The three-stage CDR process will be more time-consuming than the current two-stage process, which usually involves a recommendation from a provincial expert committee and then approval by the drug plan managers. Because the provinces will re-review the submissions anyway, CDR only adds an enormous additional layer of bureaucracy.

The mandate of the CDR Directorate is to "improve efficiencies" in the system of formulary-related reviews. The mandate of this organization should be to improve timely access to safe and effective new medicines for Canadians.

Another issue is the systematic exclusion of consumers from all aspects of the development and implementation of the Common Drug Review. Consumers are not represented on the board, and they weren't even allowed to nominate representatives to the CEDAC scientific advisory committee. The National Institute for Clinical Excellence (NICE) in the United Kingdom, which has been conducting a common drug review process for several years, not only allows patient and caregiver input but has just announced the creation of a Citizens Council to provide advice to its decision makers. Transparency and inclusiveness are essential if the CDR is to serve the public as both patients and taxpayers.

British Columbia is among the worst provinces for putting drugs on the formulary.

As currently constituted, the CDR process lacks transparency. Their only apparent criteria for a recommendation will be cost-effectiveness, which has not been defined. It is not clear whether they will be considering quality of life outcomes, improvements in disability, or other benefits of drugs, which may be equally efficacious in a strictly clinical sense.

As for inclusiveness, most of the people involved with CDR as scientific and policy advisors are the same people advising provincial drug plan managers. In other words, a huge conflict of interest exists because the drug plan managers are essentially advising themselves.

Another cause for concern is that accountability is vague. While the CDR Directorate is a creation of the provincial Ministers of Health, they will be relying on the CDR process for a recommendation. And recommendation is all it is because the final decision rests with each province. In other words, responsibility will be passed like a hot potato between the provinces and the CDR Directorate. Because the CDR Directorate is not a federal initiative in any way, Health Canada has no jurisdiction.

How CDR will affect antiretrovirals

In British Columbia, antiretroviral medications are not technically part of the formulary system. The province gives the BC Centre for Excellence in HIV/AIDS an envelope of money to buy antiretrovirals with—which they do, distributing them and continuously monitoring their uses and side effects. Antiretrovirals in BC will, therefore, probably not be subject to the CDR process—yet. However, many other provinces and territories (excluding Alberta) will have to wait for a new antiretroviral drug to get through the CDR process before they will even consider them. Any other drug that you get through the provincial formulary system will have to go through, and get through, the process. And remember, private drug plans increasingly rely on what the provincial formulary covers as an indication of what to cover themselves.

Although the CDR process was supposed to begin in 2003, they have not yet reviewed a submission. A temporary process is in place that will soon be supplanted. So far, it has caused provinces to delay listing drugs such as Pegetron. The CEDAC just met for the first time in November 2003. The CDR Directorate is planning an evaluation of itself for the fall of 2004. How consumers will have input into that process remains unclear. How likely the CDR process is to change is also unclear.

Despite being excluded, consumers have actually had some impact. The Canadian Treatment Action Council, along with the Consumer Advocare Network, the Canadian Hemophilia Society, and the Best Medicines Coalition, submitted twenty recommendations to the CDR Directorate. In response, the CDR Directorate made changes to enable a priority review system for drugs used to treat life-threatening or life-altering diseases, such as HIV/AIDS, arthritis, and cancer. It also introduced an appeal process. Consumers can take credit for forcing these changes.

Pharmaceutical products are rapidly becoming the leading expenditure of healthcare budgets. Pharmaceutical products are also increasingly allowing people to live longer, healthier lives. To what extent does the government have an obligation to provide life-saving medications or drugs that improve quality of life? Obviously, the government must respond to rising expenditures and increased healthcare needs in a balanced manner.

Perhaps one option for consideration would be to implement Recommendation 38 of the Romanow Commission Report, which calls for the implementation of a national formulary. One thing is for certain: With only two staff left at BC PharmaCare, don't expect anything to happen soon. ⊕

Paula Braitstein is the senior policy advisor on health promotion for the BCPWA Society.

Baby boom

The challenges of HIV and reproduction

by Shari Margolese

So you want to have a baby? Considering that the majority of people with HIV in Canada are of reproductive age, it comes as no surprise. Advances in HIV care and treatment have many PWAs looking toward the future and deciding to have the babies they always wanted.

The good news is that with treatment the likelihood of mother-to-child transmission can be reduced from 25 percent to below 2 percent. In addition, studies have shown that being pregnant will not make HIV progress faster.

The bad news is that recent research reveals that HIV-positive women may find it more difficult to conceive than their HIV-negative counterparts. HIV, its treatment, and co-infection with other sexually transmitted diseases may all contribute to infertility.

Recent research reveals that HIV-positive women may find it more difficult to conceive than their HIV-negative counterparts.

Conception is also of particular concern for serodiscordant couples—that is, couples in which one partner is HIV-positive and the other is HIV-negative. Safe sex is recommended, but that, of course, prevents pregnancy. In many cases, serodiscordant couples will require access to reproductive technologies, such as in-vitro fertilization, donor eggs, and sperm washing, in order to conceive.

When the female is HIV-positive, it is possible to collect semen from the HIV-negative male for artificial insemination. This procedure can usually be done at home, but it may require the assistance of a doctor. When the man is HIV-positive and the woman is not, the process becomes more complicated. Semen, which contains sperm, also contains HIV. In order to reduce the risk of transmission of HIV, the sperm must be isolated from the semen and "washed." Sperm washing must be done in a laboratory.

Unfortunately, it is not possible to remove all viral particles from washed sperm. However, research shows that transmission is unlikely. Dr. Mark Sauer of Columbia University found that in 350 couples that underwent more than 1000 inseminations of washed sperm, no HIV infections occurred in either the women or babies.

HIV-positive couples who require the assistance of reproductive technologies to conceive are very limited in their access to care. In the US, the Special Program of Assisted Reproduction until recently only permitted in-vitro fertilization of HIV-positive washed sperm. The procedure costs about US$7000 per ovulation cycle. In 2002, the recommendations were updated to include the in-utero method of insemination.

Many medical facilities refuse to implant any embryo in an HIV-positive woman, fearing infection of the child.

Access to information regarding the availability of reproductive technologies for HIV-positive Canadians is very limited. However, reports indicate that for ethical reasons Canada prohibits access to most reproductive technology for HIV-positive people. One clinic known to provide limited fertility services (sperm washing) for HIV-positive men is Southern Ontario Fertility Technologies in London, Ontario. (Visit their website at <www.soft-infertility.com>.) Other countries that may offer sperm washing and other technologies on a limited basis to Canadian couples include Italy, Spain, and the US. ⊕

Resources:

Addressing the Fertility Needs of HIV Serodiscordant Couples: <www.blsmeetings.net/1729/Speaker%20Presentations/Mark%20Sauer.pdf>

Reducing the Risks of Conception: Getting Pregnant When One or Both Partners is HIV+: <www.positivewords.com>

HIV and Pregnancy: <www.bcpwa.org/issue6/HIVPreg.htm>

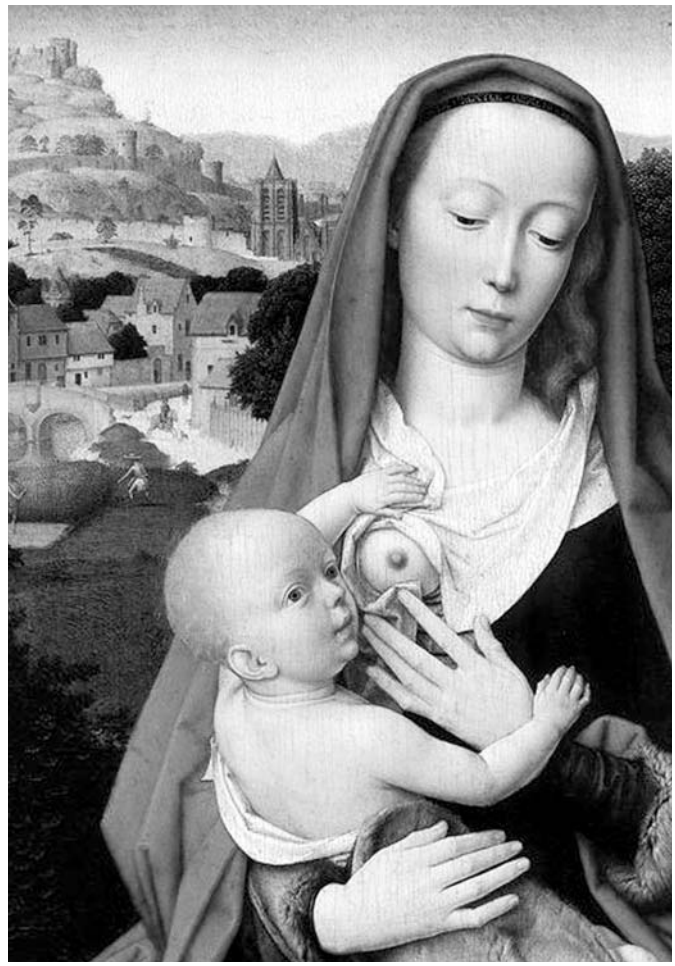
CBC News: Genetics And Reproduction: <www.cbc.ca/news/indepth/background/rgtech.html>

Shari Margolese has been a PWA advocate for 10 years and is currently the national women's representative on the Canadian Treatment Action Council.

Is breast still best?

Debating breastfeeding and HIV transmission in developing countries

by Pamela Fergusson



Is breast still best? Just when babies, mothers, nutritionists, and the World Health Organization (WHO) finally agreed on the benefits of breastfeeding, HIV infection had us reaching for the formula cans again. But ideal nutrition solutions are not found in cans. Currently, debate in the international nutrition community is raging about infant feeding and HIV/AIDS. The dramatic increase in exposure to HIV for women and children, especially in developing countries, means that policies currently under development will affect millions of lives.

In September 2000, Canada and other member states of the United Nations agreed to the millennium development goals. One goal was to increase the number of children living past age five by 60% by the year 2015. In low-income countries, one child in 11 dies before his or her fifth birthday, compared with one child in 143 in high-income countries. Although the global under-five mortality rate has declined dramatically over the past 50 years, this trend is beginning to slow, and in some countries with high HIV prevalence, it has reversed.

Infant mortality rates on the rise

HIV/AIDS is responsible for much of this reversal. International and national health programs in most high HIV prevalence areas are overwhelmed trying to respond to the pandemic. Though sub-Saharan Africa makes up only 11 percent of the world's population, it is home to three-quarters of all people living with HIV/AIDS. Over half are women, and that proportion is increasing. As more women become infected, the rate of infection in children through mother-to-child transmission is growing. According to UNAIDS, children living with HIV/AIDS numbered 3,200,000 as of December 2002. Eighty-seven percent of those children were from sub-Saharan Africa. An estimated 550,000 of them died in 2002.

The HIV/AIDS prevalence rates in sub-Saharan Africa and Southeast Asia are unequalled in the history of the disease. Although mother-to-child transmission of HIV occurs in Canada, the numbers are much smaller and are on the decline.

HIV can be transmitted from a mother to her child while she is pregnant, during delivery, and through breastfeeding. A 2002 report on HIV and infant feeding prepared by the World Alliance for Breastfeeding Action and UNICEF provided the following illustration. Imagine 100 HIV-positive women. In the absence of interventions to prevent transmission, you would expect seven of their infants to be infected with HIV during pregnancy. Another 15 would become infected at birth, and over the course of two years of breastfeeding, another 15 would become HIV-positive. Even with two years of breastfeeding, 63 of those children would not be infected. Interventions such as antiretrovirals and exclusive breastfeeding can further reduce the number of children infected.

The pervasive effect of HIV

If approximately 63 of every 100 children born to HIV-infected mothers do not contract the virus, even without treatment, why are so many children dying? In fact, many more die from the secondary effects of HIV. Children from AIDS-affected households face increased risk of becoming orphans and developing other diseases. They are also more likely to suffer poverty, food insecurity, social stigma, and decreased access to education. Thus, HIV has a pervasive effect on childhood mortality. The issue of transmission through breastfeeding cannot be dealt with in isolation. Improving child survival can only be achieved by increasing the

health, capacity, agency, and the quality of life of their mothers.

Instead of focusing on reducing the number of children infected by HIV, perhaps we should focus on the comprehensive goal of increasing child survival. An article in the June 2003 issue of *Lancet* estimated that 13 percent of child deaths worldwide could be prevented through breastfeeding. This figure takes into account mortality associated with mother-to-child transmission.

Breastfeeding increases chances of survival

Breastfeeding is one of the most powerful influences on child survival. Another Lancet article in their child survival series stated, "Infants aged 0-5 months who are not breastfed have seven-fold and five-fold increased risks of death from diarrhea and pneumonia, respectively, compared with infants who are exclusively breastfed."

Policy makers are working to integrate research with best practices to improve the health of infants at risk for exposure to HIV. The concept of exclusive breastfeeding is gaining credibility in scientific circles as a possible way to reduce the risk of transmitting HIV in breast milk. With exclusive breastfeeding, a baby consumes nothing but breast milk, not even water. Studies in South Africa show that babies who exclusively breastfeed develop lower rates of HIV infection than babies who consume a combination of breast milk and other foods. Although further research is needed to confirm these findings, many researchers and international health organizations are optimistic about the protective effects for HIV-positive mothers living in environments where they cannot meet conditions for safer artificial feeding.

The WHO addressed the difficult issue of making recommendations on breastfeeding in their 2003 publication, *Infant Feeding and HIV: Framework for Priority Action.*

> Infants should be exclusively breastfed for the first six months of life to achieve optimal growth, development and health. Thereafter, infants should receive nutritionally adequate and safe complementary foods while breastfeeding continues up to 24 months or beyond. However, given the need to reduce the risk of HIV transmission to infants while minimizing the risk of other causes of morbidity and mortality, the guidelines also state that *"when replacement feeding is acceptable, feasible, affordable, sustainable and safe, avoidance of all breastfeeding by HIV-infected mothers is recommended. Otherwise, exclusive breastfeeding is recommended during the first months of life"* and should then be discontinued as soon as feasible. To help HIV-positive mothers make the best choice, they should receive counselling that includes information about both the risks and benefits of various infant feeding options based on local assessments, and guidance in selecting the most suitable option for their situation. They should also have access to follow-up care and support, including family planning and nutritional support.

Diarrhea and pneumonia are greater dangers

Infants of HIV-positive mothers who breastfeed do have an increased risk of dying from HIV. However, that risk is small when compared with the risks of dying from diseases associated in poor countries with not breastfeeding. Less than 5 percent of global child mortality is directly related to HIV/AIDS, but diarrhea and pneumonia, two diseases strongly associated with lack of breastfeeding, together are responsible for almost half of child deaths. Breastfeeding can still be seen as protective in developing countries, even for children of HIV-positive women.

Fortunately for Canadians, most HIV-positive women in industrialized countries do not need to make difficult decisions to minimize the risk of mortality associated with infant feeding. While some Canadian women living in low-resource settings may struggle to provide replacement feeding that is acceptable, feasible, affordable, sustainable, and safe, most can meet the WHO recommendations for replacement feeding. Most of us can afford expensive baby formula, have access to safe water for preparing the formula, and can obtain the power required to boil and sterilize baby bottles and bottle nipples. Some HIV-positive women may even choose to pump and heat-treat their breast milk to kill the HIV before feeding it to their babies.

HIV has a pervasive effect on childhood mortality. The issue of transmission through breastfeeding cannot be dealt with in isolation.

Most women in developing countries are not able to provide safe artificial feeding. Studies in Africa have shown that baby bottles often contain diluted formula, water, or tea with honey in place of formula. They have also been shown to contain unsafe levels of micro-organisms. Babies ingest bacteria and consume inadequate amounts of nutrients, which can lead to serious illness or death.

As we consider the effects that HIV/AIDS has on our lives, let's also consider the effect it has on our families, our children, our communities, our country, and our world. The pandemic of HIV/AIDS is changing global economics, demographics, politics, and health. The changes can be seen most powerfully in the lives of the world's children. The recipe for solving the problem of mother-to-child transmission is not as simple as two scoops of powder mixed with a cup of water. We must work together as global citizens to create food and income security, access to healthcare, healthier environments, better education, and opportunities for children and families. Only then will we see reductions in childhood HIV/AIDS and increased child survival. ⊕

Pamela Fergusson is a Vancouver nutritionist. She is currently completing a master's degree in international health in Sweden, exploring HIV and nutrition issues in the developing world.

Positively imprisoned

Life as an inmate with HIV and hepatitis C

by Terry Howard

Remember, for a moment, when you first learned you were HIV-positive. Remember how the world just closed in around you and how relieved you were when you realized it was just in your head. Now imagine that your world really is closed in, and bars and barbed wire keep you there.

People with HIV must face the fear of telling friends and family, but for HIV-positive prisoners that fear is compounded by the real risk of being beaten or killed. And although most PWAs are able to access help and resources, inmates with HIV face the chilling prospect of little or no medical treatment, no one to help them cope with the news, and no one to talk with about what will happen to them. HIV-positive prisoners who happen to be drug users will probably find that they have hepatitis C as well. If they contracted HIV as a result of a violent rape, they won't be able to tell anyone. They will just have to cope with it the best way they can.

For HIV-positive prisoners, the fear of telling friends is compounded by the real risk of being beaten or killed.

Right now in BC, federal prisons house 3300 inmates, and another 2000 are kept in provincial correctional centres. These numbers do not take into account inmates living in halfway houses or treatment facilities or those on probation or parole. If you consider that the average length of stay of an inmate in BC provincial jails is 17 days and that a minimum stay in federal prisons is two years, you can easily imagine the vast number of inmates who are circulating through the system and returning to your community every day.

A very large number of these people are HIV and hepatitis C co-infected. The majority of them either don't know they are positive or they are unable to disclose their status because of their circumstances. This huge problem needs to be addressed quickly, compassionately, and effectively.

The vast majority of these inmates became infected in prison by sharing needles for injecting drugs. Many are believed to have contracted hepatitis C through tattooing equipment while in a federal prison. It is a federal offence to give or receive a tattoo in prison, so if caught, inmates can be charged. If a tattoo becomes infected from poor, unsterilized equipment or toxic ink, then seeking medical help could result in being charged. Inmates, therefore, just take their chances and hope infections clear up on their own.

Faced with this dilemma, it would seem that an effective means of addressing this enormous problem would be the implementation of a safe injection facility/needle exchange program, with all the necessary support services to deal with addiction. Several more studies have confirmed the benefits of establishing inmate-run safe tattooing facilities inside prisons, where the cost of running such programs could be recovered by inmates paying for the service and learning an employable trade before their release date. Nevertheless, in spite of national recommendations, successful pilot programs worldwide since 1997, and plummeting new infection rates at these pilot sites, Canada's prison system still has no safe injection sites or needle exchange programs.

Why not give these strategies for preventing HIV infection a try? There is everything to gain!

Becoming infected with HIV and hepatitis C through drug use in prison is not just a legal and medical issue, it is a human rights one. ⊕

BCPWA Society's Prison Outreach Program (POP) provides free support, advocacy, treatment information, and education to HIV-positive inmates throughout the prison system in BC.

Terry Howard is the Prison Outreach Program coordinator for the BCPWA Society.

Understanding your viral load results

by Zoran Stjepanovic

At the BCPWA Society's Treatment Information Program (TIP) office, we often receive inquiries from members about their bloodwork results. Viral load is a common concern because when viral load increases, people begin to think about starting to take HIV medications. Here are some important issues to consider when receiving your viral load results.

Look at trends over time instead of making decisions based on one test result. Viral load is only one measure of HIV progression. You must consider your CD4 cell count as well. Decisions to start antiretroviral therapy are made by looking at both viral load and CD4 cell count.

A three-fold change in your viral load whole number is considered significant. For example, if your viral load increases from 20,000 to 50,000 copies, that is not considered a significant finding. However, if your viral load increases from 20,000 to 60,000 copies, that is significant because the increase is three times your original viral load. In terms of viral load log value, 0.5 log change is considered significant. The TIP office has a viral load log value chart, which provides further information on this kind of measurement.

You may get differing viral load results if you go to a different lab. Methods or equipment may vary from lab to lab, and these differences can result in viral load measurements varying by as much as 20 percent. If you cannot use the same lab, you may need to establish a new viral load baseline at the new lab. If you see a dramatic difference in your lab results, you may want to ask your doctor whether the lab or type of test used was the same as the one used to establish your baseline. Q-PCR, bDNA, and NASBA are the most commonly used viral load tests. The Q-PCR test is the most sensitive and can detect very low levels of virus in the blood. The bDNA test is more accurate in quantifying high levels of the virus. On average, the Q-PCR test gives viral load values twice as high as the bDNA.

Viral load test results can also vary according to the time of day your blood is drawn. If you have your blood drawn in the mornings, then have future blood tests in the mornings to ensure consistency. Exercising or smoking before your test may also have some impact on your blood results.

Avoid getting a viral load test for six weeks after a vaccination or after an illness such as the flu or a herpes outbreak. The immune system is stimulated by these kinds of illnesses, and HIV becomes more active, causing the viral load to rise. It may take up to six weeks for HIV levels to return to a baseline after an illness or vaccination.

If your viral load has changed dramatically since your last test, ask to have the test done again. Testing errors can occur. The possibility of errors demonstrates the importance of not drawing conclusions from a single lab result. Look for trends over time.

It is also important to remember that an undetectable viral load does not mean that HIV has been eradicated from your body. It only means that the amount of HIV has been greatly reduced in the blood. Monitor your bloodwork regularly. ⊕

Zoran Stjepanovic is the coordinator of treatment information at the BCPWA Society.

Not so simpleX

Diagnosing and treating the herpes virus

by Sam Friedman

Herpes is a chronic incurable infection in which patients shed virus during both asymptomatic and symptomatic periods. Some patients ignore the symptoms, which can be very mild in some individuals. In fact, both clinicians and patients often fail to recognize the disease. When these patients do inform their healthcare providers, their condition is frequently misdiagnosed and not treated. Patients then unknowingly spread the infection.

Eight known human herpes viruses exist. Herpes simplex virus (HSV) is one of them. It is a complex, disease-causing organism with at least eight known distinct genotypes, all of which are not completely understood in their individual expressions and relationships with other serious diseases. Research has identified possible relationships between certain herpes virus genotypes and the opportunistic infections Kaposi's sarcoma and B-cell non-Hodgkin's lymphoma with large mass undifferentiated tumors.

Herpes does not cause zoster, or shingles, though it is treated with the same antiviral medications. Zoster is caused by the reactivation of the varicella-zoster virus that causes chickenpox.

Oral and genital herpes

Herpes genotypes 1 (HSV-1) and 2 (HSV-2) cause the vast majority of herpes infections. HSV-1 causes oral herpes (cold sores). HSV-2 causes genital herpes. Both HSV-1 & 2 live in nerve cells, usually under the skin. Neither virus is always active. They often remain latent, or inactive, in these cells, sometimes for many years or even a lifetime. For reasons not entirely understood, the viruses can become active and cause symptoms such as sores around the mouth (HSV-1) or near or on the genitals (HSV-2). These symptoms can come and go in what is known as episodic symptomatic infection.

Many clinicians believe that oral and genital herpes usually present as clusters of small classic ulcers that are easily recognized. However, this presentation may not be typical at all. Tears in the skin, ill-defined discharge (both oral and genital), and jock itch may be the more common presentations of illness.

During an outbreak, the virus becomes active and a cluster of small blisters, cracks, tears, or jock itch forms on the skin. Many episodic outbreaks may be preceded by an itch, a burning sensation, or both. These sores often rupture, heal, and then disappear for an indefinite period of time. In some cases, scarring may occur from these frequent outbreaks. In people with compromised immune systems, the sores can last from days to more than a month. Outbreaks can be incredibly painful. In very rare cases, herpes can spread to other parts of the body, including the eyes, throat, lungs, and brain. This situation can lead to death if treatment is not aggressive.

Researchers have long suspected herpes of having a role in the HIV epidemic but confirmatory data has only recently been presented.

Transmission of herpes

Both oral and genital herpes infections are easily transmitted through simple physical contact with an affected area. The virus is also easily transmitted through the exchange of bodily fluids during unprotected oral, penetrative, and frottage sex. Transmission is also possible during asymptomatic stages of the infection through contact of bodily fluids with mucosal membranes of all types. For example, women can transmit the virus through asymptomatic viral shedding in the cervix during unprotected sex.

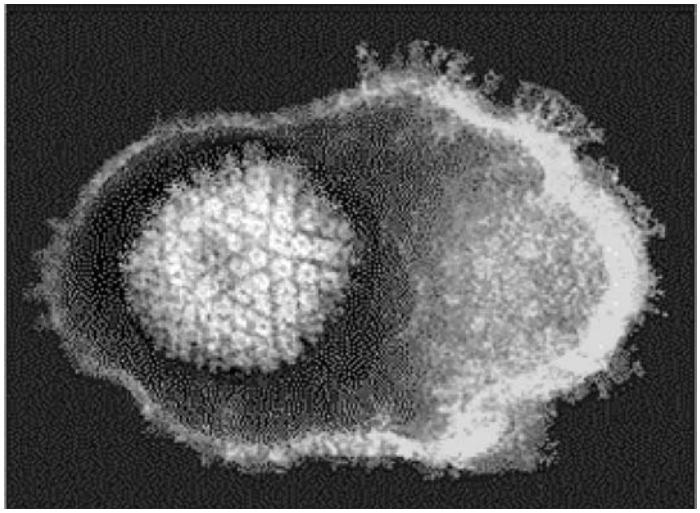
Among women who acquire herpes around the time of delivery, the risk of transmission of HSV-2 to a newborn is between 30 and 50 percent. However, the risk of transmission is lower in women with recurrent genital herpes. New guidelines recommend counselling expectant mothers to try to prevent acquisition of herpes during the third trimester and careful examination of the patient for presence of lesions at delivery. The only way to be certain of the patient's status is to perform a type-specific serologic test on the patient before delivery, preferably in the first trimester so that prevention strategies can be discussed and initiated when necessary. Physicians

vary in their method of management of patients who do acquire herpes around the time of delivery. Some recommend suppressive antiviral therapy, some recommend Cesarean section, and others recommend both.

Herpes and HIV

Researchers have long suspected herpes of having a role in the HIV epidemic, but confirmatory data has only recently been presented. A meta-analysis of 27 studies suggests that the risk of HIV acquisition doubled in persons who were HSV-2 seropositive. Conversely, persons who are seropositive for both HIV and HSV-2 transmit HIV more efficiently and have an increased rate of HIV replication.

If tears, blister-like sores, discharge of any kind, or jock itch follow these initial symptoms, you may have a herpes infection. All HIV-positive individuals should be tested for both HSV-1 & 2. A positive antibody test for either or both types is a confirmed diagnosis of a herpes infection.



The herpes virus

Diagnosis of herpes and counselling are critical to controlling the epidemic. Recent research shows that condoms, disease awareness, and suppressive antiviral therapy are all effective tools (when used together) in the prevention of both HSV-1 & 2. Patients who know that they are infected tend to change their risk behaviours and are less likely to transmit HSV to others.

New guidelines recommend the use of type-specific serologic tests to diagnose for HSV. Two new tests are now commercially available. Both measure antibodies to the glycoprotein G gene of HSV-1 & 2. These proteins vary considerably in size and composition and hence antibodies to HSV-1 gG do not cross react with antibodies to HSV-2 gG.

Treatment

Herpes infections are treated with antiviral medications. Treatment can speed up healing time, reduce pain, and delay or prevent additional outbreaks. Generally, treatment is used only during an outbreak. This approach is called episodic therapy. In people with compromised immune systems, outbreaks can be frequent and may require long-term therapy—or suppressive therapy—to prevent recurrences.

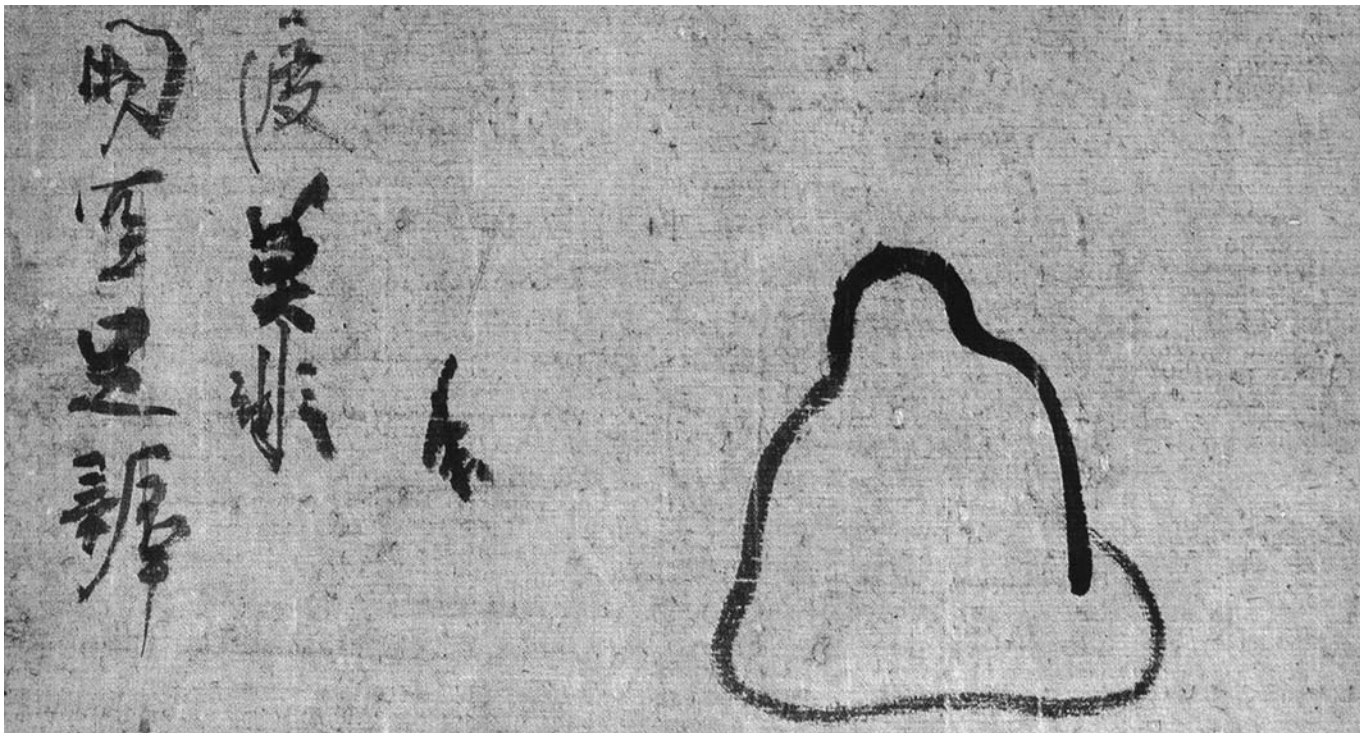
The standard duration of episodic treatment is five days, whether using acyclovir, famciclovir, or valacyclovir. However, a recent study found that a three-day course of valacyclovir (500mg twice daily) is as effective as the standard five-day regimen in terms of time to heal, pain duration, and episode length. Clinicians may therefore consider treating for shorter periods with varying doses and varying dosage frequency. All three antiviral agents—valacyclovir, acyclovir, and famciclovir—are safe for use in immunocompromised patients.

Vaccines to prevent HSV infections are currently being studied. Researchers generally believe that an effective vaccine may be available in three to five years. Vaccines will only prevent the infection from occurring in the first place. They won't help control outbreaks in patients who are already infected.

During an outbreak, it is important to keep the sores and the surrounding area as clean and as dry as possible to help the natural healing processes. To reduce pain and irritation, avoid tight-fitting undergarments. Most creams and lotions are ineffective and may even irritate the area. The drier you can keep the area, the faster it will heal. At least daily antiseptic cleansing of the area is essential to prevent the affected area from developing a secondary infection such as strep or staph.

Limited data suggest that that amino acids lysine and arginine may play a role in herpes outbreaks. According to new research, lysine can help control herpes outbreaks, but arginine can make outbreaks worse. Both these amino acids are present in many foods. Foods that are rich in lysine but low in arginine include fish, chicken, beef, lamb, milk, cheese, beans, brewer's yeast, mung bean sprouts, and most fruits and vegetables, except peas. Foods that are high in arginine and may aggravate outbreaks include gelatin, chocolate, carob, coconut, oats, whole wheat and white flour, peanuts, soybeans, and wheat germ. ⊕

Sam Friedman is a treatment information counsellor for the Treatment Information Program at the BCPWA Society.



It's all in your mind

Visualization and psychoneuroimmunology

by Ron Rosenes

I begin by assuming the position. Lying flat on my back on my yoga mat after a vigorous practice, my breathing becomes more regular. I instruct every part of my body to let go. From my toes to my eyelids, from my calves to my tongue, I check that every part of me is completely relaxed. In my mind, I turn the yoga mat into a beach of crystalline white sand that warms me from below like the sun that filters through the palms above. Cerulean blue sky stretches to infinity. Turquoise water laps lazily onto the shore. The gentle breeze carries the songs of birds. For a brief instant, the world is on "pause." I imagine that I have found the pause button for my virus as well.

Then it's back to reality, laundry, and meds. Sound flaky? Well, close your eyes and think about warm pastry crust for a moment or whatever your favourite food might be. Warning! The thought of warm strawberry-rhubarb pie or rocky road ice cream may be the road to salivation.

Perhaps you remember having a wart on your finger as a child. Then as now, the doctor might tell you to wish it away by imagining the wart virus to be under attack by Pokémon, Steel Battalion, or some other video game superhero. This approach seems to work well with kids who have vivid imaginations and fewer inhibitions than adults.

People with HIV may use visualization for many reasons. It is an effective way to manage pain caused by peripheral neuropathy. Studies also reveal it is effective as part of a program to help reduce high blood pressure, lower elevated cholesterol levels, and relieve respiratory problems associated with asthma. Its effectiveness as an anxiety reducer and depression treatment is also well documented, as is its usefulness in coping with substance abuse issues. Above all, studies show that a healthy belief system or a positive attitude reinforced by visualization techniques can have a profound effect on the immune system and its innate capacity to heal.

In the late 1980s, researchers in basic science began to wonder what was going on in the body at a cellular level. Thus, the discipline of psychoneuroimmunology, or PNI, was born.

When the body is in a relaxed state and taught to focus on persuasive images, chemicals are released that can stimulate the immune system. Chemicals that act as messengers between cells may be referred to as neurotransmitters, cytokines, or simply hormones.

The ways in which cells communicate with other cells and form messaging systems are complex but can be understood in the example of the "fight or flight" strategy that occurs as an involuntary reflex when we are confronted with danger. Similarly, the imagery of visualization can accelerate the body's production of chemical signals to the immune system, encouraging it to spring into action.

Visualization can accelerate the body's production of chemical signals to the immune system, encouraging it to spring into action.

Psychologists soon began to study how the stress of living with HIV and other psychological factors can influence health. Studies have linked depression and negative attitudes to a lowered immune system. One study at UCLA found that being closeted, or hiding one's gay identity, can add further pressure to a declining immune system. The theory is that closeted men are introverts who are especially sensitive to social rejection. They tend to go into "fight or flight" mode when facing stress, and this reaction may make them more vulnerable to HIV infection. Researchers are exploring ways of increasing levels of serotonin using visualization techniques instead of or in combination with antidepressants.

In addition to the natural response to fight or flee, a message to retreat may also be sent in threatening situations. The latest research suggests that the mind-body connection may in fact be a two-way street. According to the theory, the immune system alerts the brain to infection by releasing cytokines or chemical messenger cells that say, "Houston, we have a problem." The brain in turn releases its own cytokines that lead to a cascade of responses, including fever and listlessness, that may help the body to adapt by reducing energy output. Put in the simplest terms, you recognize when your body sends you a message, and you may be able to send one back reinforced by the use of positive images.

Sometimes my yoga instructor takes the group through a guided visualization. Some doctors and clinics also offer this technique. You may even find an AIDS service organization that offers guided imagery sessions, or you can teach yourself visualization techniques with tapes and CDs. These can be found at bookstores or ordered on the Internet from sites such as <www.healthjourneys.com>.

To my knowledge, no one has visualized HIV completely out of his or her body, but it is an excellent technique within a program of self care. It belongs with other mind-body techniques such as meditation, hypnosis, and biofeedback. I've heard that men visualize troops of soldiers and women see vacuum cleaners. For me, it's a battalion of brooms sweeping up my virus while I lie on the beach. ⊕

Ron Rosenes is vice-chair of the Sherbourne Health Centre in Toronto, a member of the boards of the Canadian Treatment Action Council and AIDS ACTION NOW!, and an honorary director of the AIDS Committee of Toronto.

Dealing with the whole person

The benefits of culturally competent care

by Arn Schilder

A recent study explored the relationship between personal identity—that is, such variables as gender and sexual orientation—and healthcare experiences among HIV-positive sexual minority males. The study involved researchers from the BC Centre for Excellence in HIV/AIDS, UBC's department of health care and epidemiology and department of pathology and laboratory medicine, the Canadian Department of Dermatology, and Leiden University Medical Center in the Netherlands. The research was conducted through a combination of focus groups, interviews, and a questionnaire.

This study included 47 HIV-positive participants from three different categories of sexual minority men: those who self-identified as gay men, those who self-identified as bisexual men, and those who self-identified as transgendered. Participants were questioned about their general healthcare experiences; their experiences of HIV antiretroviral therapy, including access and adherence issues related to these therapies; and how their identities are related to their experiences of healthcare. Three distinct themes emerged: the importance of sexual identity and its social and cultural contexts; the differences in health concerns between the different categories of men; and their wide spectrum of experiences with the healthcare system.

Identity and care

Biologic sex, gender identity, sexual orientation, and social sex-roles are the components that form human sexual identity and predict how we identify ourselves socially. Persons born as male but who either identify their gender as female or live as women identified themselves as transgendered. A male who had cultural, emotional, and sexual relations with other men, who gender-identified as a man, and who preferred to live within masculine social sex-roles identified themselves as gay. Bisexual men were reluctant to self-label as bisexual. These men often preferred invisibility and would not socially identify with the other two minorities. By contrast, healthcare providers often assume that transgendered persons are gay men in drag, that gay men gender-identified as women, and that bisexual men were gay.

There were marked differences between the groups in terms of income, education, and housing. Few participants maintained supportive ties with families of birth or origin but sought emotional and social support from families of attachment. Family was thus best defined as "those persons closest in knowledge and affection," which should be the criterion in interpreting any individual's social support.

Gay men had the strongest and most functional social networks. Transgendered persons dealt with isolation and relied on networks of peers often linked to the sex trade, which generally conspired against recovery from addiction. Because of the desire for invisibility, bisexual men had loose social support networks that were linked to the street and to substance abuse. All participants reported continued marginalization and common threats to their social safety and security because of their identities and their HIV disease. For some participants, lived reality began as a runaway with the likely introduction into the sex trade, illicit drug use, and sometimes incarceration.

Health concerns

Although profiles of disease and illness differed among the groups, each reported specific health concerns that prompted them to engage the healthcare system. Transgendered persons and bisexual men often reported injection-drug related complications such as septicemia, endocarditis, hepatitis C, and abscesses. Gay men were overall the healthiest of the three groups. Sexually transmitted diseases, hepatitis, and upper respiratory infections were concerns for younger gay men, but for older gay men conditions were associated with more advanced HIV disease.

All three groups dealt with stigma and psychological issues surrounding disease and physical disability. Mental distress was different for all groups but included histories of addiction, recovery, attempted suicide, depression, and the psychological issues associated with coming out. Transgendered persons reported isolation and psychological problems associated with gender identification and greater social stigma. Gay youth dealt with stress and psychological issues and reported feeling marginalized because of recent infection. Bisexual men's mental health issues were related to histories of childhood sexual abuse, being runaways, and having problems accessing healthcare because of a reluctance to disclose their sexual identity to healthcare providers.

Experiences with healthcare

Most participants had experienced past and present hostile or incomplete care within the health system. Participants felt they were treated as "risk factors" and were not "dealt with as a whole person." A lot of the information on this issue came from experiences in the emergency room and acute care settings. For the most part, participants anticipated prejudice from providers, but especially from care providers outside urban centres. Fears were especially prevalent about receiving care from health practitioners with religious lifestyles.

To be ethically responsive, health care professionals must deconstruct personal attitudes that may act as impediments to providing complete care.

Gay men were the most successful in developing relationships with care providers, possibly because of peer information acquired through strong community networks. Through trial and error, older gay participants were able to locate culturally competent providers who would address their health needs within their social contexts. This information was passed on to younger gay men who often described unclear boundaries with their new providers. Overall, aboriginal people, bisexual men, and transgendered individuals did not fare as well in their healthcare relationships.

Participants often reported feeling hostility towards healthcare providers because of perceived moral attitudes. Participants often reported discomfort with straight physicians. They felt that competent primary care came mostly from gay physicians and a few acculturated straight physicians. Affirmation of social identity and an accurate knowledge of sexual identity were important ingredients in the successful care-giving relationship in this sample. Adherence to antiretroviral therapy was associated with physicians exercising skilful care that affirmed the participant's social and sexual self-concept and encouraged self-help behaviours.

For the health providers, advances in HIV antiretroviral therapy have presented a series of complex social, ethical, and professional challenges that include the duties to treat, to do no harm, and to accommodate. In our view, health practice that maintains prejudicial attitudes which fail to see, or avoids including social and sexual identities, impedes access to healthcare and to life-prolonging drugs. This is an ethical and professional liability. To be ethically responsive, healthcare professionals must deconstruct personal attitudes that may act as impediments to providing complete care and address the marginalization and discrimination that act as barriers to access.

Cultural competence

Sexual minority patients reported successful therapeutic relations with healthcare practitioners who understood their social confirmation and cultural contexts. This phenomenon, known as cultural competence, has three components:

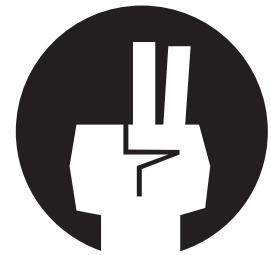
- Understanding population-specific health-related cultural beliefs and values
- Knowledge of disease incidence, prevalence, and mortality rates
- Understanding of population-specific treatment outcomes.

In this definition, medicine and the healthcare system recognize distinct populations with health disparities and intervene appropriately within their cultural contexts. Culturally competent healthcare providers have a set of congruent behaviours, attitudes, and policies to interact with their patients.

This study highlights the need for culturally competent providers. These providers identify and include the social and sexual identities of their patients, understand the specific health concerns of each group, and can anticipate the therapeutic outcomes of their interventions. This approach in healthcare is likely to reduce healthcare avoidance and improve care-seeking behaviours in these populations, thus fostering access and adherence to HIV antiretroviral therapy. ⊕

Arn Schilder is a researcher at the BC Centre for Excellence in HIV/AIDS in Vancouver and a former chair of the BCPWA Society.

GIVE P'S A CHANCE



Understanding p-values in scientific research

by Paula Braitstein

IF you have ever read a scientific research article or attended a presentation, you have probably noticed the term "p-value."

The P-value has almost mystical significance. It dictates whether a research result is statistically significant and whether it may, therefore, be the truth. In fact, nothing could be further from it.

The rather mundane truth about p-values is quite dry and, well, a little scientific. "P" stands for probability. Everything in statistics is about probability and the probability that the numbers crunched reflect, in some way, the truth about something. Simply put, a p-value is the probability that a statistical result is not a false-positive one.

Huh?

At issue here is that statistics are a way of interpreting the past to try to predict the future. In statistics, it is recognized that random errors occur just by chance. Statistics account for the fact that accidents happen.

Another way to understand p-value is that it represents the probability that the result found is due to chance. In other words, the smaller the p-value and the more zeros after the decimal point, the better.

Table 1 shows that a p-value of 0.05 means that there was a 5% (or 1 in 20) chance that a result was strictly due to chance. If the p-value is 0.001, you can conclude that there was a 1 in 1000 chance that the result was due to chance.

Table 1. Interpreting p-values.

P-value	In words	By percentage
0.10	10 in 100 or 1 in 10	10%
0.05	5 in 100 or 1 in 20	5%
0.01	1 in 100	1%
0.001	1 in 1000	0.1%

It is well known among statisticians and epidemiologists that you can use statistics to tell pretty much any story you want, which is why so much energy gets put into critiquing research methods. How you ask the question and how you measure the answer will strongly determine the results you get and, therefore, how you can and should interpret them.

Many factors can affect the size and reliability of a p-value. Always consider the following variables before drawing any firm conclusions from a result that appears to fit the holy grail of statistical significance.

- How big was the sample size? A study of 100 people will yield much stronger and more reliable results than a study of 10.
- Does statistical significance mean clinical significance? A statistically significant increase of 25 CD4 cells, for example, which falls well within the limits of the normal, inherent variability of the test, is clinically meaningless.
- How many times were the questions asked? The more times you roll a dice, the more likely you are to roll a six! The more times you ask a question, the more likely you are to get the result you are looking for. A p-value of 0.05 means that of twenty questions asked, at least one of the answers will be what you're looking for, just by chance. ⊕

Paula Braitstein is the senior policy advisor on health promotion for the BCPWA Society.

SMART study examines when to begin therapy

By Jim Boothroyd

The Canadian HIV Trials Network is gearing up to participate in the first major long-term international study that aims to provide answers to one of the most pressing clinical questions: when is the best time to start HIV antiretroviral therapy?

Known as SMART (a large, simple trial comparing two strategies for management of antiretroviral therapy), the study aims to enroll 6,000 participants at up to 350 sites worldwide, including 150 volunteers at 10 sites in Canada.

Sponsored by the American National Institute of Allergy and Infectious Diseases (AIDS Division), it is being conducted in the US through the Community Programs for Clinical Research on AIDS.

Many HIV physicians now treat their patients with daily doses of drugs to keep the amount of virus in their blood (viral load) as low as possible. This approach is effective in helping people with CD4 cell counts of less than 200–250 cells to live longer without serious diseases. However, it is not known whether this is the best way to use anti-HIV drugs to treat people with higher CD4 cell counts over many years.

SMART examines the long-term consequences of two strategies of antiretroviral management: a drug conservation (DC) strategy, in which participants only use antiretrovirals when their CD4 cell counts are below or equal to 250 cells per cubic millimetre; and a viral suppression (VS) strategy aimed at suppressing viral load as much as possible, immediately following randomization and throughout follow-up, irrespective of CD4 cell count.

Participants must be older than 13, have CD4 cell counts greater than 350 cells per cubic millimetre (when first tested), and be willing to adhere to the regimens of both study arms.

Those randomized to the DC arm will stop or defer antiretroviral therapy (ART) until their CD4 cell count slips below 250 cells per cubic millimetre, then restart treatment until their CD4 cell count rises to approximately 350 on two consecutive occasions. Thereafter, they will take ART episodically based exclusively by CD4 cell counts.

Those randomized to the VS arm will use ART to maintain viral load as low as possible regardless of CD4 cell count by changing their medications when the viral load is not suppressed.

The primary outcomes—measureable end-points of the study—will be progression to AIDS-defining illness or death. Follow-up will continue for six to nine years, the estimated time needed to observe 910 primary events.

Dr. Walter Schlech of Halifax is the principal investigator of the Canadian part of the study. Vancouver trials will be conducted by Dr. Brian Conway at the Downtown Infectious Diseases Clinic (IDC). ⊕

Jim Boothroyd is the communications manager at the Canadian HIV Trials Network.

Trials enrolling in BC

CTN 147 — Early Versus Delayed Pneumococcal Vaccination
BC sites: St. Paul's Hospital and Downtown Infectious Disease Clinic (IDC), Vancouver

CTN 157 — Fenofibrate & L-Carnitine for Elevated Triglyceride Level; *BC sites*: St. Paul's Hospital and Downtown IDC, Vancouver

CTN 164 — STI (Structured Treatment Interruption)
BC sites: Downtown IDC, Vancouver, and Cool Aid Community Health Centre, Victoria

CTN 167 — OPTIMA: Options with Antiretrovirals
BC sites: VIRON, Downtown IDC, and St. Paul's Hospital, Vancouver, and Cool Aid Community Health Centre, Victoria

CTN 169 — DAVE: D4T or Abacavir plus Vitamin Enhancement
BC site: St. Paul's Hospital, Vancouver

CTN 171— Cellcept (Mycophenolate Among Patients with HIV Receiving Abacavir)
BC site: St. Paul's Hospital, Vancouver

CTN 175 — Nevirapine to Lower Cholesterol (SCHMALTZ Trial)
BC site: St. Paul's Hospital, Vancouver

CTN 178 — Rosiglitazone Maleate (Avandia)
BC site: St. Paul's Hospital, Vancouver

CTN 183 — Continuous Treatment versus Intermittent Treatment
BC site: St. Paul's Hospital, Vancouver

To find out more about these and other trials, check out our trials database at <www.hivnet.ubc.ca/ctn.html> or call Sophie at the CTN (1.800.661.4664).

Besame, besame mucho!

por Sergio Plata

El beso es una manera de comunicarse y demostrar ternura, un beso en la diplomacia es de vital importancia, recibir, según la biblia el beso puede ser una muestra de bendición o maldición, el beso de judas es simbolo de engaño, pero otras veces con un beso podemos expresar nuestras mas elevadas perversiones.

En Griego existen dos tradiciones del beso; *Filema* es aquel beso que lleva consigo comunicacion, paz y bendicion y *Katafileo* es el beso ferviente, perverso y sexual. En Hebreo *Nashak* besar significa unión y para los orientales es una forma de recibir y dar energia espiritual.

Dicen que el beso llego de Europa donde los griegos besaban el pecho a sus superiores y los emperadores extendian suavemente la mano o la rodilla para ser besada por los campesinos. El beso entre hombres se usaba desde la edad media pero solo era permitido en una misma posicion social, sin embargo si una mujer besaba a un hombre que no fuera su marido era juzgada de adultera. Algunas tribus africanas creian que al besar el alma podia escapar por la boca.

Una teoria afirma que el beso nacio cuando se observarón a los pajaros alimentar a sus crias, otra teoria muestra que el beso es el resultado del placer de mamar, porque al besar recuerda seguridad, afecto y satisfacción que se obtenia al ser alimentado por la madre.

Un beso cuando nos despierta amor se convierte en el equilibrio perfecto entre la estimulación fisica, los pensamientos y el espiritu. Besar con pasion durante diez minutos quema 150 calorias. El actor Regys Toomey y Jane Wyman se besarón durante 185 minutos para la pelicula "You are in the army now." Jeffrey Henzler beso a 3225 mujeres en 8 horas (una cada 8.93 segs). Según una chica Estadounidense besa un promedio de 79 hombres antes de contraer matrimonio y dicen que quien se despierta cada mañana con un beso vive mas tiempo.

Existen besos de lenguita, de permanencia voluntaria, salivosos, de aspiradora, tronados, fogozos, desabridos, los deliciosos besos mañaneros, los besos negros (*anal*) y los besos del payaso que se dan cuando la mujer esta menstruando.

Cuando besamos cerramos los ojos porque se produce una dilatación en las pupilas y el cerebro nos impulsa a entonarlos. Al besar ponemos en movimiento 34 musculos y durante un beso circulan por la saliva 9 mg de agua, 0.7 gr de albumina, 0.18 gr de sustancias organicas, 0.711 mg de materias grasas, 0.45 mg. de sales, y un puñado de bacterias y enzimas.

Pero no todo es dulce saliva cuando damos un beso, porque a traves del *beso y el sexo oral* tambien se contraen un sinfin de infecciones, una de ellas es el CMV, es facil de contraer para las personas que tienen su sistema immune muy debilitado los sintomas mas comúnes son *glandulas inflamadas, cansancio, fiebre, debilidad* y en algunas personas puede provocar *perdida de la vista y transtornos mentales*, no es curable y puede controlarse con medicamentos como son el *foscarnet* y *ganciclovir*. Por la boca tambien puede entrar las bacterias de la gonorrea, en mujeres esta infeccion puede provocar *esterilidad, ardor al orinar, dolor de abdomen, pelvis y dolor durante el coito* y para los hombres aparece un *flujo purulento del canal urinario y dolor al orinar*, el 80% de las mujeres y el 10% de los hombres con gonorrea no demuestran sintomas, existe cura con antibioticos orales.

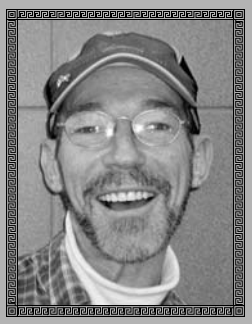
En las últimas investigaciones se ha descubierto que existe un virus llamado HHV-8 con mayor presencia en la saliva, este virus es el causante del *sarcoma* major conocido como Kaposi; este es un tumor cancerigeno que se manifiesta en forma de ampollas irritadas en la piel y en la boca, tambien puede aparecer en cavidades internas como el abdomen o el pecho, este virus es común en enfermos con *sida*.

No olvidemos que un beso puede mover montañas o despertar una fuerte pasión, pero tambien puede darnos una infección. Un beso se puede dar con la mirada, con las manos y con el corazón. Y a usted que tipo de besos le gustan mas? ⊕

BCPWA Treatment Information Program (TIP)
Ofrece información sobre tratamientos del VIH/SIDA.
Todos los miercoles 1:00PM a 5:00PM.
1107 Seymour Street, 2nd Floor, Vancouver, BC V6G 5S8
Llame a la línea directa: 604.893.2243
email: treatment@bcpwa.org

Volunteering at BCPWA

Profile of a volunteer: Ray Brunet



Ray shines as team leader of Polli & Esther's. The store looks great! Ray organized a clever system for fair distribution and a standardized method of display, all to everyone's benefit. He supports teamwork, is hardworking, smart, tenacious, and decorates a window to rival Holt's.

Jackie Haywood
Director of Support Services

Volunteer History
I began volunteering in the Membership Department of BCPWA. At first, it was mostly a means to stay active. I soon became aware of the opportunities that were opening up for me, such as learning new skills and putting my own skills to good use.

Started at BCPWA
August 2001

Why pick BCPWA?
I didn't really pick BCPWA as such. The opportunity was there. It seemed the right thing to do.

Why have you stayed?
I stay for the variety, the pleasure of being helpful to others, the daily challenges, and the sense of belonging and friendship.

Rating BCPWA
BCPWA is living up to its mandate. I have learned a lot about compassion, tolerance, respect,and empowering oneself. I truly do feel more confident, as well as a sense of higher self esteem.

Strongest point
For me, the strongest point was rediscovering myself and helping to redefine who I am—and never losing sight of where I'm going.

Favourite memory
Every activity is a good memory. However, one stands out: summer retreats.

Future vision of BCPWA
BCPWA has touched more people, affected more lives than one can imagine. I know it will keep on doing so with ever greater accomplishments.

Gain and share your skills for a valuable cause

IF YOU HAVE
- administration skills that include word-processing, or
- law and advocacy skills, or
- research and writing skills, and
- the ability to work independently and in a group,

WE CAN FIND A MATCH FOR YOU IN OUR NUMEROUS DEPARTMENTS AND PROGRAMS!

for further information and an application form **contact**:
volunteer coordination at 893.2298
adriaanv@bcpwa.org
or Human Resources at 1107 Seymour Street

visit our web-site at www.bcpwa.org for further information on volunteer positions

where to find help

If you're looking for help or information on HIV/AIDS, the following list is a starting point.

BC Persons With AIDS Society
1107 Seymour St, Vancouver BC V6B 5S8
604.893.2200 or 1.800.994.2437
info@bcpwa.org
www.bcpwa.org

A Loving Spoonful Location
Suite 100 – 1300 Richards St,
Vancouver, BC V6B 3G6
604.682.6325
clients@alovingspoonful.org
www.alovingspoonful.org

AIDS Memorial Vancouver
205 – 636 West Broadway,
Vancouver BC V5Z 1G2
604.216.7031 or 1.866.626.3700
info@aidsmemorial.ca
www.aidsmemorial.ca

AIDS Prince George
1–1563 2nd Ave,
Prince George, BC V2L 3B8
250.562.1172
ogodwin@bcgroup.net

AIDS Resource Centre – Okanagan and Region
202 – 1626 Richter Ave,
Kelowna, BC V1Y 2M3
250.862.2437 or 1.800.616.2437
arc@arcok.com; www.arcok.com

AIDS Society of Kamloops
P.O. Box 1064, 437 Lansdowne St,
Kamloops, BC V2C 6H2
250.372.7585 or 1.800.661.7541
ask@telus.net

AIDS Vancouver
1107 Seymour St, Vancouver BC V6B 5S8
604.893.2201
av@aidsvancouver.org
www.aidsvancouver.bc.ca

AIDS Vancouver Island (Nanaimo)
201 – 55 Victoria Rd, Nanaimo, BC V9R 5N9

AIDS Vancouver Island (Victoria)
1601 Blanshard St, Victoria, BC V8W 2J5
info@avi.org; www.avi.org

ANKORS (Nelson)
101 Baker St, Nelson, BC V1L 4H1
250.505.5506 or 1.800.421.AIDS
info@ankors.bc.ca
http://kics.bc.ca/~ankors/

ANKORS (Cranbrook)
205 – 14th Ave N Cranbrook,
BC V1C 3W3
250.426.3383 or 1.800.421.AIDS
gary@ankors.bc.ca
http://kics.bc.ca/~ankors/

Asian Society for the Intervention of AIDS (ASIA)
210 – 119 West Pender St,
Vancouver, BC V6B 1S5
604.669.5567
asia@asia.bc.ca, www.asia.bc.ca

Dr Peter Centre
1100 Comox St,
Vancouver, BC V6E 1K5
604.608.1874
info@drpeter.org; www.drpeter.org

Friends for Life Society
1459 Barclay St, Vancouver, BC V6G 1J6
604.682.5992
ffl@radiant.net
www.friendsforlife.ca

Healing Our Spirit
Suite 100 – 2425 Quebec St,
Vancouver, BC V5T 4L6
604.879.8884 or 1.800.336.9726
info@healingourspirit.org
healingourspirit.org

McLaren Housing Society
200 – 649 Helmcken St,
Vancouver, BC V6B 5R1
604.669.4090
mclarenhousing@telus.net

North Island AIDS (Campbell River) Society
684B Island Hwy,
Campbell River, BC V9W 2C3
250.830.0787 or 1.877.650.8787

North Island AIDS (Courtenay) Society
355 6th St, Courtenay, BC V9N 1M2
250.338.7400 or 1.877.311.7400

North Island AIDS (Port Hardy) Society
8635 Granville St, Ground Floor,
Port Hardy, BC V0N 2P0
250.902.2238
niac@island.net; www.island.net/~niac

Okanagan Aboriginal AIDS Society
202 – 1626 Richter Street,
Kelowna, BC V1Y 2M3
250.862.2481 or 1.800.616.2437
oaas@arcok.com; www.oaas.ca

Outreach Prince Rupert
300 3rd Ave. West
Prince Rupert, BC V8J 1L4
t 250.627.8823
f 250.624.7591
aidspr@rapidnet.net

Pacific AIDS Network c/o AIDS Vancouver Island (Victoria)
250.881.5663
erikages@pan.ca; www.pan.ca

Positive Living North West
Box 4368 Smithers, BC V0J 2N0
3862 F Broadway, Smithers BC
250.877.0042 or 1.886.877.0042
plnw@bulkley.net

Positive Women's Network
614 – 1033 Davie St, Vancouver, BC V6E 1M7
604.692.3000 or 1.866.692.3001
pwn@pwn.bc.ca; www.pwn.bc.ca

Red Road HIV/AIDS Network Society
Suite 100 – 2425 Quebec St,
Vancouver, BC V5T 4L6
604.879.8884 or 1.800.336.9726
info@red-road.org; www.red-road.org

Vancouver Native Health Society
441 East Hastings St, Vancouver, BC V6G 1B4
604.254.9949
vnhs@shaw.ca

Victoria AIDS Respite Care Society
330–1105 Pandora, Victoria, BC V8V 3P9
250.388.6620
varcs@islandnet.com
www.islandnet.com/~varcs/

Victoria Persons With AIDS Society
541 Herald St., Victoria BC V8W 1S5
250.382.7927
support@vpwas.com; www.vpwas.com

Wings Housing Society
12 – 1041 Comox St, Vancouver, BC V6E 1K1
604.899.5405
info@wingshousing.bc.ca
www.wingshousing.bc.ca

YouthCO AIDS Society
203 – 319 Pender Street,
Vancouver BC V6B 1T4
604.688.1441 1.877.968.8426
info@youthco.org; www.youthco.org

For more comprehensive listings of groups, societies, programs and institutions in British Columbia serving people touched by HIV disease and AIDS, please visit the Positively Happening section of the BCPWA Society website at www.bcpwa.org.

Upcoming BCPWA Society Board Meetings:

Date	Time	Location	Reports to be presented
January 7, 2004	1:00	Board Room	Standing Committee — Financial Statements / November
January 21, 2004	1:00	Board Room	Written Executive Director Report — Director of Prevention
February 4, 2004	1:00	Board Room	Quarterly Department Reports — Executive Committee — Financial Statements / December
February 18, 2004	1:00	Board Room	Written Executive Director Report — Standing Committee — Director of Communications & Education
March 3, 2004	1:00	Board Room	Financial Statements / January — Director of Treatment Information & Advocacy
March 17, 2004	1:00	Board Room	Written Executive Director Report — Executive Committee — Director of Support Services
March 31, 2004	1:00	Board Room	Financial Statements / February — Standing Committee

The BCPWA Society is located at 1107 Seymour St., 2nd Floor, Vancouver.
For more information, contact:
Alexandra Regier, Office Manager
Direct: 604.893.2292
Email: alexr@bcpwa.org

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❍ I am a PWA in BC and can not afford the full subscription price
❍ Enclosed is my donation of $_____ for *living+*
❍ Please send me more information about Planned Giving
❍ I want to become a member of BCPWA

Cheque payable to BCPWA

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1107 Seymour Street, 2nd Floor
Vancouver, BC
Canada V6B 5S8

Public probe

A lesson on exposing your… feelings

by Mark O'Hara

"From our personal struggles and challenges come our courage and strength."
I had not thought much about this part of the BCPWA Society mission statement until recently. It sums up my adventure with Theatre Positive, BCPWA Society's theatre company. What began as a journey of self-expression soon became a trial of my own courage and a challenge to overcome my recent diagnosis of clinical depression.

It started at the beginning of August. Our fringe festival production of "West End Stories" was taking shape. The day began with our ritualistic check-in, a time to clear the mind of clutter and make room for the day's events. One by one, we took our turn speaking. People's mouths were moving, but not a thought registered in my head. The only words that I remember are the ones I was about to speak.

I was supposed to stand there with my pants around my ankles and take this? "Jeez Brian, it's roomy in there!"

"For the first time in a long time, I can say that I feel nothing. Today, I started taking antidepressants." The only thing I could really feel was the warm, tingly numbness from my new friend, Celexa. "Hello, hello…." My wires were definitely crossed.

After the check-in and a quick physical warm-up, cast and crew sat down to learn our respective fates. The script had no shortage of male roles, so I knew I would end up with a full plate. Of the three roles I was cast to play, one would present a great challenge. That was the role of Brian in "Heartland." Brian is a thirty-something, positive gay male stuck in rural BC. What did I know about rural life? Here we go again. Twenty years ago, I fled the narrow-minded small town world to lose myself in the freedom of big city life.

That night, I tackled my homework. I was to dissect Brian from head to toe. What made him tick? Who was he? How did he feel? How could he endure the uncaring and heartless small town quack? Why did he put up with all the insults? Brian was a mere object in his physician's eyes, a small obstacle that was keeping the good doctor from a rousing round of golf.

What about the nelly medical student and his unusual form of support? I was supposed to stand there with my pants around my ankles and take this? "Jeez Brian, it's roomy in there!" This was going to be a very public probe.

After several hours of finding nothing but questions, I decided to watch some television. "It's My Party" was on the late show, so I gave my lack of emotions a test. This movie has always made me sob like a child. By the end of the film, I was guaranteed to be a blithering fool. Not this time. I discovered my emotions were truly out of whack. The tear-jerking moments in the film elicited a mad sort of laughter. Near the end, I was consumed by such hysterical laughter that tears rolled down my face. "Do the sheep really care?" I was unsure if I would make it to our fast-approaching opening night.

We put on our performances. Some laughed and others cried. Finally, it was time for our last curtain. I was more concerned with tripping over my lines than sudden bouts of laughter. The wardrobe master gave me a compelling speech about an old closing night tradition, and I agreed to pull the prank. Just before I took to the stage for my final public probe, the wardrobe master handed me a soaking wet wad of paper towels. I quickly held it to my underwear and then tossed it into the garbage can. Before I knew it, the show was over. "Bah, Bah…." Not much was said about the wet spot.

From my personal struggle, I have found the courage and the strength to overcome another challenge that comes with living with this virus. After all, it's not everyday that a man can stand with his pants around his ankles in the name of his society. ⊕

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